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Exhibiting Pain: Creative Representations of Life with Chronic Pain

Thesis submitted for the degree of Doctor of Philosophy

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The Open University

July 2020

Exhibiting PAIN

Creative Representations of Life with Chronic Pain



Susanne Amanda Main

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Abstract

This work provides an exploration of the effects of sharing creative representations of life with chronic physical pain. Social media platforms (Facebook and WordPress) have been used to carry out the research, hosting two online galleries of creative works depicting life with chronic physical pain. Comments on the works, and discussions surrounding them, have been examined to show how different audiences respond to the works, according to whether or not they have pain. In keeping with the postmodern epistemology underpinning this research, issues of interpretation and multiple interpretations have been considered. In addition, responses have been assessed to consider how effective such works are in communicating the experience of living with this invisible and subjective condition. My role as a researcher with chronic physical pain is explored in relation to the use of reflexivity in carrying out the research. The conflict involved in seeking empathy and recognition of experiences living with pain, while balancing this with the desire to keep this personal experience private and the feeling that other people do not want to hear about the condition, is discussed in relation to the concept of public-private dualism. Issues regarding the elicitation of empathy and understanding with the creators' experiences are considered in the light of the creative works. In addition, the benefits arising from sharing such works in online exhibitions are highlighted, demonstrating the potential for creative approaches to the expression of pain to facilitate the effective communication of the experience.

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Chapter One: Introducing pain

Introduction

This thesis presents an exploration into the role that creativity may play in facilitating effective communication of the chronic pain experience. The creative representations, by 23 people with pain, have been featured in two online galleries, using social media platforms. I will situate the research in the current field of literature, demonstrating what it contributes regarding new knowledge and suggestions for future practice and study. When discussing the findings in the thesis, I draw upon issues surrounding the interpretations of creative works, together with the elicitation of empathy and the difficulties of balancing the public and private aspects of living with persistent physical pain.

This introductory chapter sets out the problem to be addressed, which concerns how the subjective condition of persistent physical pain can be understood by other people, given its individual and invisible nature. The difficulties of understanding and communicating the condition, and how to share it to receive support and understanding, are demonstrated. The methods applied to this study are noted below, followed by details about terminology used, the influence of my own long-term physical pain and the structure of the thesis is then described. I begin by setting out a definition of chronic pain and demonstrating the difficulties of expressing the experience of living with the condition.

The problem with pain

The International Association for the Study of Pain (IASP) defines pain as:

An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (2017).

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Chronic, or persistent, pain is that which has lasted beyond three months and is believed to affect approximately 20% of the global population (Butler & Moseley, 2012). There have been calls to update the IASP definition to allow for recognition of the social dimensions of pain, alongside the sensory and emotional ones (Carr, 2018). My own experiences lead me to believe that pain sensation exists primarily in the moment. However, the other aspects of a chronic pain experience, such as the psychological, social and emotional impacts, persist even when the severity of pain sensations ebb. Chronic pain conditions are often characterised by widespread varying pains which may fluctuate at differing times. Hence, while the experience of living with long-term pain is persistent, the sensations may be in flux. This inconsistency and unpredictability of symptoms is part of what makes living with pain so difficult and distressing for the individual (and their support network). The feeling of being unable to describe pain effectively or fully may add to fears of being deemed a malingerer or attention seeker. The inability to recall or describe accurately the sensations can create a sense of crisis for individuals who may begin to doubt themselves (Gotlib, 2013). This suggests that there is a need for individuals to recognise and validate their own pain experiences internally, as well as seeking such recognition from external sources. However, the problems in achieving this are exacerbated by the difficulties communicating pain.

Effective communication between an observer and the person in pain is important in helping to ease the pain experience (de la Vega et al., 2018). Kunz et al. (2018) state that the main reasons for wishing to communicate the experience of pain is 'to solicit help, support, and empathy responses' from the social environment (2018: 109). The personal and invisible nature of persistent pain creates a world that cannot be known by others (Good, 1992), heightening the loneliness experienced with the condition. Such loneliness, isolation and difficulties in communicating are described by Birk (2013), who writes of her own experiences with pain:

It had become the kind of pain that frequently prevents you from going out [...] the kind of pain that makes it difficult [...] even to just finish a sentence (2013: 394)

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Birk shows that the difficulties in communicating pain are not solely to do with finding the right descriptors or explaining the subjective experience but also, at times, in piecing words together into coherent sentences.

Different arguments are made concerning the availability of language and voice in talking about pain experiences, together with the willingness to talk about it. Scarry (1985) argues that those with pain are reduced to 'a state anterior to language, to the sounds and cries a human being makes before language is learned' (1985: 5). There is a need to communicate pain when seeking relief and medical treatment but an individual may be left feeling tongue-tied. As Biro notes, in *The Language of Pain*, 'expressing pain seems impossible' (Biro, 2010: 12), leaving people unsure 'how to describe what feels so immediate and yet so intangible' (2010: 13). Birk, who wrote an autoethnography, describes how, at the height of her pain, she found herself 'unable to find words that could articulate the shape of [her] suffering' (2013: 396). Likewise, 19th Century French novelist Daudet wrote, 'words only come when everything is over' (2002: 15), that they refer to memory and do not flow when pain is at its worst. Consequently, Daudet states, words are powerless or misleading. Birk argues that when pain ebbs people may regain their voice but rarely wish to recall the suffering, 'so pain remains, more often than not, unspoken' (Birk, 2013: 396). However, for others, pain can generate language and does not appear to fracture it, unless at the threshold of acute pain (Stoddard Holmes & Chambers, 2005). Hide et al. (2012) note that rather than being resistant to language, as Scarry (1985) claimed, bodily pain can generate language and creative expression, while Bending (cited in de Montalk, 2019) asserted that Scarry's claims are likely to increase a feeling of helplessness in those living with pain. Thereby demonstrating that identifying methods which help people with pain to express their experience is likely to be helpful.

Gotlib (2013), writing of chronic pain and identity, states that chronic pain is made unique partly through the lack of a shareable language that can communicate the experience adequately. Antelo (2013), in a piece about Frieda Kahlo's artworks and pain, concurs that the subjective experience of the condition can be impossible to

convey, leading to dissatisfaction for patients in their interactions with clinicians. Sörensdotter (2013) states that it is possible to listen to the words and body language in a narrative, but it is hard to 'actually reach and fully understand the bodily experience of being in pain' (2013: 62). Consequently, while the words and their meaning may be understood by another person, the felt experience of living with pain cannot truly be understood by anyone else, due to its subjective nature. In interviews with Sörensdotter, women (who have vulvar pain) showed how their pain affects their lives using facial expressions, hands, and their whole bodies, stating 'bodies tell stories about pain together with vocal language' (Sörensdotter, 2013: 62). This argument accords with the research of Rowbotham et al. (Rowbotham et al., 2014a; Rowbotham et al., 2014b), who demonstrate that people report greater difficulty communicating when pain is more intense, but that there is also an increase in spontaneous verbal communication and co-speech gestures¹. It is established in the field of pain management that co-speech gestures and pain behaviours are frequently used to express symptoms (Rowbotham, et al., 2014a). Established strategies for improving communication, regarding pain, are scarce, note de la Vega et al. (2018). For example, it may be that there is potential to harness other modes of communication for a broader representation, but this possibility remains largely unexplored. It would be helpful to investigate this to identify potential benefits that may arise through an enhanced expression of chronic physical pain.

Pain does not only resist linguistic representation, writes Tarr (2018), but also the attempts to 'standardise and measure it in any consistent, coherent way' (2018: 233). One assessment measure, which relies upon the person's self-report of pain for completion, is the McGill Pain Questionnaire (Melzack & Wall, 1996); it is used widely by clinicians to investigate the intensity and quality of pain (for example, throbbing, pinching, burning) (Kunz et al., 2018). In doing so, attempts are made to create a

¹ Co-speech gestures are spontaneously produced communicative movements of hands, arms and other body parts alongside speech. In relation to pain, these may convey location, size and sensation of the pain which are not included in the accompanying speech (Rowbotham et al., 2014b).

quantitative, standardised, measure of pain which is reductionist in nature, ignoring the subjective experience of the condition, together with the impact of pain on the individual's quality of life. This relies upon cognitive and language capabilities, disadvantaging those with dementia, children and some people with learning difficulties (Kunz et al., 2018). From a patient's perspective these words can also feel unrepresentative of the pain sensations or restrictive in choices. Kunz et al. (2018) note that there may be self-report biases, as questionnaire responses are less spontaneous, not necessarily being recorded at the same time as the pain sensations are being experienced.

Thompson (2016) writes that the invisibility of pain means that 'internal, private experiences must be articulated and revealed' (2016: 310) in order for people external to the individual with pain to know that pain is being experienced. Therefore, the person describing their pain must be taken at their word. As a consequence of appearing 'normal', many people with chronic pain feel stigmatised (Thompson, 2016). There is therefore an apparent need for people with pain to feel that their story is credible. This need is seemingly unique to people with chronic pain (Clarke and Iphofen, 2008). It is necessary for people to perform their pain, in order to be deemed credible (Birk, 2013), because of its invisible nature. However, the performative nature of the behaviour creates more doubt in the observer (Birk, 2013). Some pain behaviours (for example, posture or self-soothing actions) may serve physical or protective functions, while other forms of verbal and nonverbal communication (such as facial expressions) serve mainly to inform our social environment about our inner state, namely the experience of pain (Kunz et al., 2018: 101).

There are three ways in which chronic pain can be silencing, according to Birk (2013). One of these is due to its invisible nature, as the reliance upon self-reporting and pain behaviours causes a loss of credibility in the process. Secondly, a lack of straightforward aetiology and clear diagnoses can create scepticism and lead to stigmatisation, furthering the isolation that occurs with the condition. Finally, pain's inherent resistance to language, combined with the effect of medication on speech

and thought, creates 'an existential crisis that demands to be communicated even as it disables one's capacity for such communication' (Birk, 2013: 392). Such a paradox contributes to the distress experienced when living with persistent pain.

The topic of stigma is also discussed by Sheppard (2019), who writes that people with chronic pain experience a dual stigma in failing to be 'normal,' together with the stigma of being in pain; consequently they are forced to engage in stigma management alongside pain management. Sheppard argues that it is not that expressions of pain are not understood, but they are ignored deliberately due to an unwillingness to 'catch' pain (2019). Consequently, the person with pain is obligated to control their pain, and their expression of it (Sheppard, 2019). While Sheppard is demonstrating that there are difficulties in expressing pain in an accepted way, she is also arguing that part of this difficulty is due to the unwillingness of people to bear witness to others' pain. Together these complications in finding ways to express pain, and to hear it, are illustrative of some reasons why people with pain are conflicted in whether or not, and how, to express pain publicly. While Sheppard's arguments are concerned with hearing and responding to pain, I will explore, in the next section, whether this communication may be facilitated by approaching it with a creative or multimodal approach.

The potential of creative approaches

Wickelgren (1989) commented that an exhibition of 'headache art' enabled many migraine-prone viewers to realise that they were not alone; she also argues that the works enabled these viewers to see their experience of migraines as a 'legitimate' disorder. In keeping with this, it will be investigated here whether online exhibitions of creative representations of life with chronic pain can be effective in helping to tackle the sense of isolation and not feeling understood which is experienced by many people living with the condition. Additionally, this research will investigate whether the acts of sharing and viewing such works can help to reduce isolation.

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Broadbent et al. (2009) argue that using creative methods to communicate experiences may lead to the expression of feelings and thoughts that are outside the range of some questionnaires, such as the McGill Pain Questionnaire (Melzack & Wall, 1996). As an alternative, creative methods may aid people to express themselves 'without words' (Bullington, et al., 2005: 272), while Morris (1991) asserts that physical, emotional and mental pain can generate creative material for 'personal and artistic triumph' (1991: 194). My research will explore whether creative techniques can be used to express chronic pain and aid communication of the experience, with the potential to elicit empathic responses.

Linked to empathic responses to pain, de Montalk asks, if it is not possible to feel another person's pain, 'is it possible to imagine or understand it?' (2019: 190). It may be, however, that there is not a requirement to imagine or understand it in order to recognise or empathise with another individual's personal experience of pain. Seeing other people in pain can provoke an automatic empathic reaction, reports Craig (2018), as well as evoking a reflective effort to understand what is happening to that individual. This may be achieved because observing or witnessing pain leads people to make reference to themselves, signalling a threat to one's own safety and motivating avoidance behaviour (Kunz et al., 2018), as Sheppard suggested about people's fear of 'catching' pain (2019). While the individual may feel cut off from the world by their pain, Biro writes that 'the world turns away from the sufferer just as consistently as the sufferer turns away from the world' (2010: 30). Social bonds, roles and etiquette may, however, counterbalance the personal instinct for avoidance, argue Kunz et al. (2018). It would therefore be helpful to consider how the inclination for avoidance of witnessing pain may be overcome and whether this might be achieved through creative means of communication.

It is an objectification of pain which Padfield partly achieves through photographic images of pain (2003). Padfield argues that images (specifically photographs) provide a 'shared reference point' (Padfield, 2003: 20) which clinician and patient can use to aid communication. Padfield argues that the use of an object moves discussion between

clinician and patient away from the patient to focus on a third-party object (Padfield, et al., 2010). Discussion is focussed on the card's representation of pain, or the patient's ability to relate to that image, rather than on the individual's experience directly. As a result, the person is able to talk more clearly about their pain, taking greater control of the clinical encounter. This suggests that objectifying pain can help to communicate the experience of living with the condition.

Beyond illustrating symptoms, visualisations of pain are of value as 'vivid testimonies' to the condition's importance and helping it to become shareable (Hurwitz, 2003: 12). Creative representations of the experience of chronic pain can assist health professionals to grasp the nature of the experience, helping to improve patient care (2003). A visual language for pain is one possible means through which to facilitate meaningful communication of the experience (Novartis Pharma AG, 2003). Psychiatric patients have used art to depict images in their minds, providing health professionals with a way to understand the person's illness more clearly (Staricoff, 2006). One artist (not featured in this research project), whose work is on the PAIN Exhibit website (PAIN Exhibit, Inc., 2015b), reports that her voice contributes to her medical records through the incorporation of a copy of her artwork (Yolland, 2015). This suggests that the use of creativity may also empower individuals to communicate their experience of chronic pain, by enabling them to express their pain.

Participation in crafts and art therapy can be effective interventions, having therapeutic benefits. Art can be used as a form of communication, writes Bucciarelli (2016), while the creative process itself can be therapeutic. These occupations can also function as a pain management tool, through the facilitation of distraction from pain. Other benefits include an association with wellbeing and good mental health (Angheluta & Lee, 2011; Stuckey & Nobel, 2010; Collen, 2005). Creative pursuits facilitate autonomy and wellbeing (Perruzza & Kinsella, 2010), which may motivate an individual to use these methods to represent their chronic pain experience. Many research participants stated to Reynolds (2004) that artwork assisted them to find and express their voice. Where finding suitable language to communicate the experience

of persistent pain is an issue, the potential use of creative methods to facilitate an understanding of the condition becomes more significant. It is established that creative techniques may be used as part of art therapy (guided by a practitioner and used to explore issues with a patient) or as a distraction technique in managing chronic pain (Butler and Moseley, 2012). However, the use of creativity to express and communicate life with chronic pain is worth researching – both as a topic and as an approach to generating data, to see if there is scope to expand how creativity is currently used in relation to pain.

Visual drawing methods have been applied in other related fields, for example to understand illness experiences such as headaches (see Wickelgren, 1989; Broadbent, et al., 2009); as participatory arts methods (for example, Clark, 2011); and in research with children (such as Guillemin, 2004). Other research in the field has used visual methods alongside interviews to explore the viewpoint of the participant (for example, Henare et al., 2003). An interpretative phenomenological analysis of drawings by people with persistent pain was carried out, alongside interviews about their portrayals, by Kirkham et al. (2015). While Phillips et al.'s research (2015) provided an open question survey format, allowing participants to add any comments about their drawings, Kirkham et al. (2015) go a step further, since the picture produced is presented alongside an interview with the creator. This is similar to photo-elicitation methods in that interview data is gathered using the participants' images to generate discussion (for example, Radley and Taylor, 2003; Radley, 2002; Han and Oliffe, 2015). Bendelow (2000) asserts that visual imagery techniques are of value to explore possible differences between perceptions of health professionals and users of health services. All of these studies argue, as Pain (2012) does, that the use of visual methods (whether or not in combination with interviews) adds richness to data and enables insights not possible without the visual element. Consequently, there are precedents to the use of visual methods in exploring areas of illness and pain but these have focussed about the production of images specifically for the purposes of research studies, rather than those created outside of research. The work presented here uses works already created about an individual's experience with pain and presents these

for consideration by viewing audiences, as discussed in Chapter Three: Method and methodology.

Terminology

The terms ‘chronic’ and ‘persistent’ are used interchangeably throughout the thesis and sometimes omitted altogether in favour of the single word ‘pain’, all are used in reference to long-term physical pain. Where short-term, acute, mental or emotional pain is being referred to, this is specifically described as such. When discussing the findings, acronyms are used to describe the individual’s pain status as this is perceived to be relevant to their understandings of pain in the context of this research study. These are provided as follows:

C	Creator – creator contributing to the original gallery, rather than including those with pain who shared their works in the Facebook group
P	Pained participant – lives with chronic physical pain
NP	Non-pained participant – does not have chronic pain
PU	Pain status unknown
PRO	Professional connection to the field of chronic pain – used in addition to pain status, where applicable
PA	Personal Acquaintance – used in addition to pain status, where applicable

I have avoided use of gendered terminology, pronouns and pseudonyms when discussing creators or other participants, in acknowledgement that some noted a preference not to use either male or female terms. Some participants specifically avoided answering the question (on the consent form’s demographic survey) despite options including ‘prefer not to say’ and ‘other preferred term’, although they

answered other questions. Additionally, one participant noted that they are hermaphrodite. Although the use of 'they/them' can be somewhat distancing and impersonal, I felt on balance it was more appropriate to avoid all gendered terminology.

The creators of the works featured in *Exhibiting Pain* are called 'creators' rather than 'artists' to avoid concerns of whether the individuals self-define as artists or their works as art (by themselves or others). It was also used to encompass creators of all mediums, such as poetry as well as the visual arts. The use of 'creator' also enables a greater focus on the act of creation and that the individuals created the works themselves, rather than in collaboration with an artist.

Structure of this thesis

The next chapter of the thesis, Chapter Two: Existing literature related to the experiences of chronic pain and its expression, will introduce the literature regarding the nature of chronic physical pain as a personal and subjective experience, the arts health field and the role of creativity in communicating chronic pain. Discussions regarding the interpretation of creative works will be presented as well as showing the need for empathy and validation for those living with pain who live with a conflict about the private nature of pain and whether or not to show it publicly. Gaps in the literature will be identified before the following chapter presents the research design and method.

Development of the research questions is shown in Chapter Three's Method and Methodology, together with an exploration of the epistemological approach of postmodernism underlying the thesis. The research design is described and details of how this was carried out are provided. Some details of the unusual method are contextualised within literature to demonstrate the research supporting the decision to follow this approach to data collection; for example, in terms of the use of

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exhibitions and social media as a platform to carry out research. The establishment of galleries and data collection processes are described, together with the redundant contingency plan for data collection, had it been required.

The role of my position as a researcher with chronic pain is discussed in Chapter Four, to allow transparency of the influence of this on the research. The intention when starting the doctorate was not to include my own experiences in the research or thesis, apart from through a passing acknowledgement. However, as discussed in Chapter Four, it became apparent during the research process that the influence of my pain on my role as researcher was more significant than I had anticipated and it was necessary to give this due consideration. To provide transparency and insight into the influence of my pain on the research, throughout the thesis my personal reflections are provided inside bordered text boxes, using courier font. These are not labelled as they are not referred to directly. Instead, they form an 'adjunct' to demonstrate the influences of my pain and experiences on my thinking through the research process.

Chapter Four, therefore, provides details of my own experiences living with chronic physical pain. This chapter follows the method because it has influenced the data collection and analysis processes but does not precede the method chapter as I had not intended to include such details prior to writing up the thesis. This chapter also includes a discussion of vulnerability in the researcher and the difficulties involved in researching and writing about chronic pain, while living with the condition.

Chapter Five provides a discussion of the ethical considerations involved in online and arts-based health research. It also considers the ethics involved in researching and exhibiting works about chronic pain. For example, avoiding apparent exploitation of those living with the condition. University ethical approval will be discussed, together with concerns regarding the copyright of exhibits. Privacy issues with online methods are discussed, together with the ethics of utilising my personal acquaintances as

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participants in the research. The chapter concludes by describing difficulties I experienced with one participant who was abusive and threatening.

Chapters Six and Seven form the two findings chapters. The first of these, Chapter Six, is concerned with the act of creating works about life with chronic pain and the way in which pain is expressed in the creative works. It goes on to discuss the public-private 'dualism' that I suggest exists in living with pain. Chapter Seven develops the findings in relation to the exhibition of the creative works and how these were responded to by audience members. This is taken on to a discussion about the elicitation of empathy through the sharing of the creative works and the connection to the validation of pain experiences.

Finally, Chapter Eight provides a discussion of how findings presented in the thesis go towards addressing the research questions. The findings will be summarised in relation to literature about the role of creativity in communicating pain, the elicitation of empathy and validation and the conflict experienced in sharing private pain in a public context. This chapter provides recommendations for future research and considers the potential to develop the work in relation to the literature identified. It will present my reflections on the limitations of this study and considers the impact which it has.

Conclusion

This first chapter has introduced some of the complexities involved in living with chronic pain in order to contextualise what will follow. It has been shown that the invisible nature of pain can cause people to feel stigmatised and struggle to find others who are willing to bear witness to their pain. While there are difficulties in finding ways to express pain, other problems to be tackled include how to do so in a manner that appears acceptable to others and is effective in eliciting empathic understanding. This touches upon the difficulties of living with an invisible and personally subjective condition, which people are reluctant to hear about, while feeling a need for validation

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of the experience and therefore needing to publicly display the experience. These issues will be revisited through the discussion that follows. The next chapter will present the literature in the field, highlighting gaps in knowledge.

Chapter Two: Existing literature related to the experiences of chronic pain and its expression

Introduction

The literature which is reviewed critically here allows me to demonstrate the need for a study exploring how creative methods may aid communication of the experience of living with chronic physical pain, by being shared through online exhibitions. Two key issues regarding life with chronic pain are focussed upon in the literature presented. One issue is the difficulties related to the expression of the experience of living with the condition. The second is about the perceived lack of understanding regarding the experience of living with persistent pain and the sense of not being believed. The literature relating to these issues will be explored and gaps in knowledge highlighted. The role of creativity in representing persistent pain will be considered, together with the need to examine how such representations are interpreted by different audiences. Additionally, the role that exhibitions may have, both in research and in raising awareness about health conditions, will be considered. I begin by illustrating the intrinsic difficulties regarding the expression of chronic physical pain because of its personal and subjective nature. This moves to consider the role that the arts may have in the field of health and research, and specifically in expressing pain. Following this, communication in clinical encounters is discussed and research aimed at aiding this process using the arts is presented. The role of creativity and interpretations of images are discussed before showing how these may help to make pain public. Issues of stigma, impression management and emotion work are also considered, in relation to the display of chronic pain. Together, the literature presented is used to show the gaps which exist in these areas and the need for research which may help to address this.

Pain as a private experience

Pain is a subjective experience which ‘only becomes accessible by being expressed’ (Kunz et al., 2018: 102). Stewart argues that attempts to express personal experiences ‘fall short of the mark through words alone’ (Stewart, 2016: 347). Metaphors, and particularly visual expressions, argues Stewart, enable a shared communication beyond words. Vocabularies available for describing pain are rather limited however and may ‘seem inadequate in the face of the feeling’ (Ahmed, 2014: 22). Kunz et al. (2018) list forms of expressing pain as including facial expressions, body movements, nonverbal vocalisations, such as moaning, or verbal statements, for example, ‘I am in pain’. The use of the arts as a form of communication and expression is not addressed by the authors.

Biro writes that pain isolates us from friends and family as no one could feel what he could and the ‘inability to find words for my feelings only exacerbated my loneliness’ (Biro, 2010: 5). Pain is described as silencing and experienced as impossible to express in language by Käll, despite the even stronger desire to speak in an attempt to gain relief (2013). Articulating pain provides relief in part because it ‘restores a relation to the world severed by pain’ (Käll, 2013: 31) and language can provide community where there was previously isolation (Biro, 2010). It is clear that for both Biro and Käll, the expression of pain reconnects those living with it to people around them, helping to reduce the isolation.

It is the private nature of pain, writes Ahmed (2014), that creates a link to others, as such a personal experience generates a loneliness which requires the pain to be disclosed to a witness. As no one can experience another person’s pain, this can lead to the desire for others to acknowledge the feeling. Consequently, the solitary nature of living with pain is tied up with its ‘implication in relationship to others,’ leading Ahmed to note that, ‘while the experience of pain may be solitary, it is never private’ (2014: 29). Ahmed continues by discussing her personal experience of living with her mother’s pain and bearing witness to it, ‘I would look at her and see her pain’ (2014:

29). Demonstrating that while a person may feel their pain is not visible or recognised, this may not be the experience of those close to them who are attuned to changes in demeanour, posture and behaviour.

People with chronic pain experience what Bullington et al. describe as 'chaotic disintegration' (2003: 330), leading to the breakdown of a personal narrative, unable to know one's self or to relate to others. This links to Bury's discussion of the impact of illness as 'biographical disruption,' requiring that expectations of future life and selfhood be re-evaluated (1982). Skultans (1998) argues that narratives facilitate the construction of new meanings, when those held previously have become redundant. Consequently, the process of constructing a new narrative may allow the disrupted self to be remade. However, where language has been 'shattered' (Scarry, 1985: 5), or the ability to provide a coherent narrative has been lost, such processes may prove elusive to the individual with chronic pain. The difficulties of narrating the experience of pain are explored by Mintz (2011).

The need for flexibility and creativity when communicating pain experiences is demonstrated by Mintz (2011). The natural inclination, she writes, is to 'narrate ourselves in the form of story' (2011: 243), with recognisable structures, such as a narrative arc with climaxes and resolution. However, as pain eludes description and interferes with plot, the forward motion of a life story is disrupted because pain pursues 'its own narrative trajectory' (2011: 244). Pain narratives are described by Bayliss (1998: 75) as 'pouring out [...] in a haphazard way [...] without structured thought.' Likewise, de Montalk (2019: 5) also describes the difficulties of forming structured flowing narratives about pain, compared to what she considers to be the spontaneous fragmented 'tellings' that may occur online. Birk (2013) notes a similar experience when writing an autoethnography of her own chronic pain experiences. She states that narratives are difficult because her writing is fractured: 'my language had become too chaotic and nonlinear for others to follow' (Birk, 2013: 396). It is for these reasons that Mintz (2011) argues for the lyric essay as possibly the most suitable autobiographical genre for pain. Mintz describes the lyric essay as elusive, imagistic,

discontinuous, 'more often circling, symbolizing, and echoing life events than writing them out in causal, chronological ways' (2011: 245). This demonstrates that a creative approach to expressing pain, whether in the form of essay or alternative means, may be appropriate.

Previously, I have carried out an analysis of artworks on the PAIN Exhibit website for a MSc dissertation (Main, 2013). The analysis was carried out through application of Arthur Frank's illness narrative typologies² (1995) to the creative works, to explore the validity of applying the typologies to visual works representing chronic pain. In doing so, I noted that just as narratives can be re-worked through repeated tellings (Good, 1994), art can also be re-worked, and so the formation of the representation may be amended and developed over time (Main, 2014). While narratives can be re-worked, in the moment of being recorded by a clinician (or researcher), the telling is spontaneous and, as such, may not always form an 'ordered story' (Thomas-MacLean, 2004). Consequently, creative formats may be more appropriate as they remove the necessity for a discernible structure or plot (Main, 2014). I suggested that the typologies were of limited value in analysing the artworks because they did not allow sufficiently for the nature of chronic pain and did not transfer fully to the artistic format, unless accompanied by text. In this regard, research that interviewed creators alongside their work(s) may be better suited for an application, and assessment, of Frank's typologies to a creative format of illness representation.

The relief of having someone who wanted to listen was the motivation of Sörensdotter's (2013) participants in sharing their experiences of vestibulitis. Other motivations included the wish to contribute to research and raising the level of knowledge and awareness about their condition. However, a few wanted to tell their

² Frank suggested a typology of illness narratives that includes three categories. First, the 'Restitution' narrative, which reflects a 'desire to get well and stay well' (Frank, 1995: 78). The 'Chaos' narrative consists of imagining life never getting better (1995); while 'Quest' narrators 'accept illness and seek to use it' [sic], believing that there is something to be gained through the experience (1995: 115).

stories in order to share their experiences with others, mentioning that they had been helped by knowing there were other people with similar experiences (2013: 62). The need to be heard and to relate their stories for others' benefit is commented upon by Sörensdotter who writes that 'the physical pain becomes a social pain affecting identity when it changes the outer expression of oneself' (2013: 66). This statement suggests that it may be possible to resolve issues relating to identity and social pain, arising out of living with persistent physical pain, through the articulation of one's experience. However, Sheppard (2019) reports that her research participants stated that speaking about pain was not the problem, the difficulty they experience is people's reluctance and trouble in *hearing* about another's pain. As a topic of conversation, Jackson notes that chronic pain can cause 'numbing boredom' (2005: 231) for both the observer and person experiencing the pain. Consequently, it is important to consider ways in which people living with pain may be able to express their experiences and feel that they are heard, while balancing this with other peoples' reluctance to hear or listen to them. This is something which a creative approach may help to address and it would be of value to explore that possibility. It is the listening to pain which David Biro (a physician who also has a background in literature and medical humanities) has written about, drawing on stories of others' experiences with pain as well as his own.

Pain is deemed unshareable and others' pain unknowable through its lack of objectification. Scarry (1985) notes that other interior states are accompanied by objects in the world external to us. For example, we feel love or hate *for* somebody or something, fear *of* something or someone (1985: 5). However, physical pain is internal and cannot be directed at something away from ourselves, potentially increasing the associated distress of the pain. Contemporary social media members attempt to find ways to objectify and publicly show this internal pain through the practice of selfies³, also demonstrating the realities of invisible illnesses in response to the commonly cited remark, 'But you don't look sick'; for example, the #HospitalGlam movement (King,

3 'Selfies' are photographs taken of the person by themselves, usually with a smartphone.

2016) and a series of photos with captions showing 'what fibromyalgia looks like' (The Mighty, 2017). While such practices may help to challenge stigmatising notions of what someone who is 'sick' or in pain 'should' look like, they may not directly address the expression of the experience itself. In the latter case, The Mighty's YouTube video of photos by people living with Fibromyalgia, the captions provide a large insight into the meaning behind the image. Consequently, it would be helpful to know if other creative and/or visual representations of pain require accompanying text to understand the experience being represented.

Giving meaning to the self-in-pain requires attention to be paid to the ways in which pain is made meaningful in the first place, making some communicative act crucial (Mintz, 2011). Mintz states that no single scale could accurately represent pain, nor is one explanatory system sufficient to understand the meaning of pain. Similarly, Morris refers to 'postmodern pain' which uses 'multiple systems or subsystems of explanation, each with its own distinctive language or discourse, none of which holds absolute priority' (Morris, 1991: 283). It follows that no single format for expressing pain would be sufficient either and that it may be appropriate to draw upon multiple modes and techniques simultaneously, demonstrating the need to explore whether such a multimodal approach to the expression of pain may be effective in eliciting understanding.

Arts and health field

It is important to distinguish between arts therapies and the arts for health field. Art therapy is a form of therapeutic intervention informed by disciplines of psychology, psychotherapy and psychiatry, with a professional body providing practice guidelines (Broderick, 2011, cited in Chatterjee and Noble, 2013). However, the arts for health (or, arts *in* health) field includes a broader range of possible benefits, such as social cohesion, reduced anxiety and pain levels, and increased self-confidence, among others (Chatterjee & Noble, 2013). There are many issues for which the arts have limited relevance (Clift & Camic, 2016). However, Clift and Camic (2016) argue that at

heart they are about creativity and problem-solving, and about creating meaning and beauty in peoples' lives. Such skills and benefits, to be gained through the arts, may be of benefit in learning to manage and communicate chronic pain; it would be helpful to know if this is the experience that people with pain have in using creative activities.

Exhibitions have been used in qualitative research primarily as a means of disseminating findings (for example, Bruce, et al., 2013). However, more broadly, exhibitions have been used in the field of health to raise awareness about issues, such as mental health (Chung, et al., 2009). Also, the PAIN Exhibit (PAIN Exhibit, Inc., 2015a) website seeks, through an online exhibition of art, to educate its audience about the experience of living with chronic physical pain (Collen, 2005). On this theme, exhibitions help to make human experiences concrete, argues Ott (2010), so that others can learn from them. Carden-Coyne (2010) warns that the pain of others can sometimes distance audiences rather than inform them. While Ott (2010) suggests that visitors may be aware of the content previously, but viewing items in an exhibition context can provoke unexpected emotional responses. Consequently, research on the effect of exhibitions regarding health matters, and more specifically chronic pain, on the audience would be of value. This could include the possible distancing of the audience and if the works provoke fresh responses in people. Such information might help to inform what role exhibitions could have in increasing understanding about living with chronic physical pain, and other health conditions.

As the arts can expand opportunities for representation, a more fully embodied response is invited from audiences (Cox & Boydell, 2016). This is enabled through the multiple levels of engagement that are possible, such as cognitive, sensory, emotional and aesthetic (Cox & Boydell, 2016). Sonke and Lee (2016) observe that culture and creative formats (such as images, theatre, song and dance) can provide meaning to health information, significantly aiding understanding and use of the information. In this way, the arts, argue Sonke and Lee, can help to address individual and public health needs. An example is provided by Kasule et al. (2016) who report that Lillian Nabulime's use of sculpture, in the context of social practice, raises awareness for HIV

and its prevention. Demonstrating that sculpture can be instrumental in providing education about a condition, especially where there may be high rates of illiteracy or social taboos surrounding discussion of some topics (Kasule et al., 2016). Visual and artistic communication methods can therefore provide culturally sensitive forms of engaging with people while potentially transmitting powerful and important messages (Wells, 2016). Consequently, it would be helpful to consider how this may translate specifically to raising awareness of the condition of chronic physical pain.

The 'Communicating Chronic Pain' project by Tarr et al. (Tarr et al., 2014; Gonzalez-Polledo & Tarr, 2014; Tarr, Cornish, & Gonzalez-Polledo, 2018; Tarr, Gonzalez-Polledo, & Cornish, 2018) explored the use of innovative multidisciplinary methods of research applied to the topic of communicating pain. This included a series of visual and performing arts workshops; it also entailed the output of a small book featuring images and written contributions by both participants and researchers, followed by an edited volume in 2018. When presenting this work at conference in 2014, the team stated that they had not hosted an exhibition of the works created because they wished to avoid an emphasis being placed on the 'product' resulting from the workshops. As their funding was for a project testing innovative multidisciplinary methods it is appropriate that they wished to avoid focusing on a creative product. However, it would have been interesting to see items featured in an exhibition, exploring alternative means of communicating chronic pain and to reflect on how these were received by audience members.

The fields of disability studies and museum studies have explored representations of ill health and advocated the social role of exhibitions (Chatterjee & Noble, 2013; Siebers, 2010; Sandell, et al., 2010; Sandell, 2002). I believe that there is scope to develop this to encompass personal health experiences. For example, Figure 1, p. 23 presents one scene from The Science Museum's *Glimpses of Medical History* display (Science Museum, n.d.).



Figure 1 'Helping the disabled in 1980'

(The Science Museum, n.d., photograph author's own, 2015)

This diorama illustrates the traditional museological inclination towards showing disabled people as requiring help or as defined by the impairment they live with. The use of the title 'Helping *the* disabled' [my emphasis] removes a focus from individual experiences and follows a biomedical approach to disabled people, where there is a need to provide medical treatment and assistance to a passive patient (Hellin, 2002); additionally, impairments or illness are viewed as abnormal or undesirable. Reconstructions tend to fix strong visual images in the visitor's mind and are thus responsible for creating or perpetuating myths and illusions (Gazi, 2014: 6). Consequently, there should be a question over not only *what* is reconstructed but also *how* it is done, for whom and with what purpose (Gazi, 2014). A move is needed to represent individual stories and more personal experiences of illness and/or disability, to shift focus in exhibitions to person-centred approaches, away from the biomedical (which focus on what is wrong with the physical body). By doing so, the ability to evoke empathy may be greater. In turn, this might increase understanding of living with a particular condition and/or as a disabled person, giving voice to the individual and

challenging assumptions about life with conditions such as chronic pain. It would therefore be helpful to explore the extent to which this may be achieved by sharing creative works created by people about their own experiences of chronic pain.

Dodd writes that 'an art gallery seems an unlikely place to embark on a journey of understanding of a medical condition' (Dodd, 2002: 182). However, she states that Jo Spence's photographs of her experiences with breast cancer present insight into something widely experienced but often hidden from view. Consequently, Dodd argues that art can play a 'bold role' in 'helping people to see the universality of disease and ill health, to open dialogues' (2002: 183). There has been an increase in research in this area since Dodd wrote in 2002 that evidence of the impact that museums can have, through exhibitions and public debate of health issues, is largely anecdotal. For example, Chatterjee et al. (2017) have promoted a Museums on Prescription programme which encourages people to visit museums as part of a health intervention. Artefacts and objects are able to elicit responses from people, write Chatterjee and Noble, discussing Silverman (2002, cited in Chatterjee and Noble, 2013). Museums may help to reinforce a sense of self and connection to others (ibid.). I suggest this may be the case more broadly with exhibitions and collections of creative works. This is of particular note for those with chronic pain who may be experiencing a sense of isolation and feeling their experiences are not understood by others. Additionally, inclusion of the medical humanities into medical training has helped to develop greater communication and observation skills, as well as increasing empathy and humanising patient experiences (Chatterjee and Noble, 2013). It is possible that there is scope to develop this work by utilising creative representations of chronic pain to help improve understanding of those living with the condition, and in order to facilitate greater empathy and validation of the person's experiences.

Writing of art in hospitals, Grayson Perry states his belief that art is good for giving aesthetic pleasure only, not for healing (2007). He questions whether most of the benefits of reducing stress, boredom, speeding recovery and retaining staff in hospitals can be achieved by other means, such as 'an old copy of Heat magazine' (Perry, 2007:

13). Perry advocates the ability of art to unsettle the viewer and provoke uncomfortable questions. He suggests that hospitals should treat visitors as adults, noting:

Part of healing might be facing up to the realities of being stuck in a fallible body. I don't want the last thing I see from my deathbed to be a jaunty painting of fishing boats (Perry, 2007: 13)

While Perry's description of the art featured in hospitals ('carefully chosen conversation pieces, preferably in cheerful colours' (ibid.)) may not be shared by others, it does demonstrate that there may be a role for art which confronts the conditions people are living with, such as chronic pain, helping them to make sense of their experiences. Consequently, it would be helpful to understand more of how people respond to viewing such works in order that there may be greater understanding as to how they might be used in clinical environments.

Coulson and Stickley (2002) present a list of ideas to develop an arts strategy in practice development, advocating the use of art and creativity to support people experiencing mental distress to express it, thereby aiding healing. However, exhibitions are mentioned only through a passing reference to visiting these where available. While it is suggested that clients may decorate health areas with their art, there is no suggestion of hosting exhibitions to provide more structured exhibition opportunities. That said, Coulson and Stickley (2002) did discuss more broadly the use of exhibitions to share art works in order to raise awareness about mental distress. A formal examination of the benefits gained by exhibiting works for the creators is not carried out by the authors. It would be helpful to know what benefits people may find in sharing their representations and creative works in exhibitions.

The arts have been used as an innovative method for carrying out research and disseminating findings of studies which utilised more traditional methods (Cox et al., 2010, cited in Cox & Boydell, 2016). However, at this time there is little critical examination concerning the use of arts in research. For example, considering the methodological, aesthetic and collaborative challenges, among others, which are

inherent in this work. Cox and Boydell (2016) note that there is a need to address the issues surrounding knowledge creation, dissemination and impact, while also considering theoretical and methodological challenges. Consequently, it would be helpful to consider how the arts may create greater understanding about life with chronic pain; as well as considering methodological challenges involved in using art about chronic pain to generate knowledge and research data.

Clinical encounters

The arts therapies (where art and creative practice is used for therapy, such as in psychotherapy, rather than for therapeutic benefits, such as distraction and for its calming nature) can help to build communication and rapport between a patient and clinician (Bucciarelli, 2016). This is achieved by enabling the patient to actively participate in treatment, facilitate meaning through expression and build awareness (ibid.). It is understandable that artists have used visual methods to communicate pain, argues Harrison (2002), because pain is such a difficult concept for people to verbalise. This is supported by Collen (2005) who notes that art has proved the most effective means by which to share his pain experience, aiding communication with clinicians and loved ones. It may follow then that Collen would disagree with Hurwitz (2003) and Scarry (1985) regarding the unshareable nature of pain; though it is through art, not language, that this became possible for him.

The PAIN Exhibit online gallery of art works (created by people who have chronic pain) was established by Collen (PAIN Exhibit, Inc., n.d.) with the purpose of educating 'healthcare providers and the public about chronic pain through art and to give a voice to the many who suffer in silence' (PAIN Exhibit, Inc., n.d., online). As such, PAIN Exhibit has shown that there is an interest in creative works about pain being shared online and that there are people who wish to have their works viewed in this way. The core function of exhibitions, argue Dodd (2002) and Ott (2010), is to present topics for consideration, acting as a form of communication (Fuentes, 2014), generating discussion and providing forums for conversation. Therefore, an exhibition may be

appropriate as a means to explore the way in which creative representations of pain are interpreted, by enabling audiences to reflect on the works and share thoughts about these in a context in which it feels appropriate to do so.

Pain is commonly underestimated by both lay observers and experienced clinicians. It may be that clinical settings are not perceived as safe and therefore the protective instinct to hide pain takes over for patients (Kunz et al., 2018: 115). Consequently, aids to their communication are likely to be useful, especially those that relieve the pressure of talking about themselves as objects of study. For example, metaphors may provide a way to understand the subjective experience of pain, argues Stewart (2016). Finding a way to elicit patient-generated metaphors may help to develop shared understandings and foster empathic connections in clinical encounters (Stewart, 2016). Similarly, this may also be achieved by talking about the pain with the aid of a referential object outside of themselves, such as an artwork. Padfield et al. have demonstrated that images of pain helped to democratise clinical encounters, as patients speak more when using cards featuring photographic representations of pain, than when they did not have them to aid discussion (Padfield & Zakrzewska, 2018; Semino, Zakrzewska, and Williams, 2017). A formal study has not been carried out, to the best of my knowledge, regarding the use of artworks created personally, in aiding consultation communication. It would be useful to consider how such works may be interpreted by audiences in order to aid patients in the design of creative representations to be used for this purpose.

An empathic response requires intersubjectivity, which ‘refers to one’s ability to interact with others in a reciprocal and mutually meaningful fashion’ (Grinnell 1983 cited in Quintner and Cohen, 2016: 287). The ‘intersubjective space’ is described as being where the most creative and authentic aspects of personal and communal life are found, including artistic expression. Empathy, suggest Quintner and Cohen (2016), is at the core of intersubjectivity because it functions as a foundation that allows someone to experience the life of the ‘other’ in an intuitive manner, without having to

emotionally share the same experience, as is the case to elicit sympathy. They go on to argue that:

through creative expression, situations can be resolved and new possibilities emerge. Thus, the clinician-patient relationship becomes a truly intersubjective one (2016: 288)

As such, creativity may be an effective way to facilitate intersubjective understandings and empathy; it would be useful to explore this gap in research in the context of chronic pain.

The role of creativity

It is necessary to consider definitions of the term 'creativity.' For something to be creative, it requires originality and effectiveness, write Runco and Jaegar (2012); though they note that there is an issue on who determines whether something is either of these things. Cropley (2011) suggests that creativity involves something new, different and effective. While Barnes (2016) states that creativity is a fundamental human attribute, involving activity which produces 'outcomes that are both original and of value' (2016: 201). Gauntlett (2011) has written on the nature of creativity and the way in which it creates connections. His own definition of the term 'creativity' includes that it is

a process which brings together at least one active mind, and the material or digital world, in the activity of making something (2011: 76)

He goes on to include mentions of it being original and the process eliciting various emotions. In addition, he adds that 'when witnessing and appreciating the output, people may sense the presence of the maker, and recognise these feelings' (2011: 76). Consequently, it seems fair to summarise a definition of creativity, for the purposes of this thesis, as a process and/or activity which produces something new that is effective in eliciting emotional responses. It would be interesting to know if creative representations of the chronic pain experience accord with Gauntlett's assertion that 'creativity is something that is *felt*, not something that needs external expert verification' (2011: 79), and if audience members viewing the works feel able to sense the creators' presence and recognise the feelings being expressed.

The concept of creativity may be applied broadly when considering the communication of pain experiences, for example through metaphors. Stewart reports Shinebourne and Smith's findings (2010, cited in Stewart, 2016) that patient-generated metaphors can function as a 'safe bridge' linguistically. This way people can 'express emotions that are too distressing to communicate literally' (Stewart, 2016: 343). Similarly, art by patients in a psychiatric hospital was praised, and the importance emphasised, for the use of it as a means of communication, described as creating a 'bridge thrown across a gulf to give us access to a world which invites our exploration' (Asbjorg & Mardsen, 1969, cited in Kasule et al., 2016: 124). It would therefore be helpful to consider if the use of metaphors and art, when representing chronic pain, might also create a 'bridge' for effective communication, as referred to by both Stewart (2016) and Kasule et al. (2016).

Commonly, patients complain of a lack of opportunities to explore the personal meanings of their pain experiences with their healthcare professionals, writes van Rysewyk (2016). Clinicians, argues Stewart, must strive to identify patients' metaphors in order to 'explore meaning, and to foster empathetic and therapeutic connections' (Stewart, 2016: 344). Using art, as Collen (2005) did, may enable the patient to have the confidence to discuss the meanings of their pain, by drawing upon visual metaphors. In the process this may enable patients and clinicians to forge stronger working relationships. Metaphors within song lyrics and poetry are often used by people to make sense of a range of experiences and so, argues Stewart (2016), they may also be used by people with pain for the same purposes. Stewart suggests that further research is needed to explore the use and therapeutic value of creative methods within clinical practice. More research is also advocated by van Rysewyk (2016), who argues that there is a need to understand how meanings of pain interact with socio-cultural systems, such as art and literature. This demonstrates a gap in the literature regarding how creativity may be used to express pain, and how these representations may be interpreted.

Visual and arts-based methods have been used to facilitate understanding of pain experiences. Ignagni and Church (2008), writing in relation to disability studies, state that the arts are a means of inclusion, affording disabled people greater participation in the process of producing knowledge. As such, using people's creative works about their pain for research purposes, and encouraging them to participate in the research itself, would afford inclusion into the production of knowledge around creative expression of life with pain. For example, work published by Phillips et al. (2015) provided a thematic analysis of adults' drawings representing their pain. The research sought, in part, to explore whether people were able to visualise their pain and if the drawings provided insight about the pain experience that was not accessible through language. While Phillips et al.'s research does not produce findings beyond what is already known about the chronic pain experience, it does conclude by arguing that this visual method helps to provide a 'shareable language for pain' (2015: 410). The co-creation of photographs of pain, argue Padfield and Zakrzewska (2018), allow for the integration of the person's pained body into the image, 'allowing their lived experience to become visible and present' (2018: 221). Consequently, the subjective experience of pain may be made shareable as it becomes real and visible to the clinician (ibid.). It would be worth exploring whether creative representations of pain might provide further insights into the pain experience than reported by Phillips et al. (2015). This might be possible by using creative works not produced for the purposes of research (therefore providing more 'authentic' representations of what the individual wished to express in that moment) and by considering how audience members, not researchers, responded to these works. In doing so, this could explore the level to which the experience becomes visible and shareable, as Padfield and Zakrzewska (2018) argue.

Deborah Padfield, a photographic artist, has collaborated with people who have persistent pain to co-create photographic representations of their experience, as touched upon above. As Padfield personally lives with chronic physical pain there may be some question over the subjectivity involved in the representations produced but a collaborative exchange with people with pain, over a period of time, was involved in the making of the items. This issue also raises the question of whether it matters if

Padfield's own experiences of pain influenced the resulting image or not given that it is not only the pain experiences which are subjective but also the interpretations of the photographs. The authors (Semino, Zakrzewska, & Williams, 2017; Padfield & Zakrzewska, 2018; Padfield, Zakrzewska, & de C. Williams, 2015) have not examined more broadly the experience of viewing and interpreting the photographs, as the focus of their research has been on the facilitation of improved clinical encounters. However, greater understanding concerning audience responses to creative representations of chronic physical pain may contribute to the field as a whole, consequently helping to increase understanding of how such works can be used in clinical encounters.

Biro writes that during his own period of pain and hospitalisation, he relied on pictures as much as on his family and pain killers (2010). He argues that mental pictures helped him to think and talk about the pain he was experiencing but also suggested ways of responding to it. There is a growing literature examining thoughts about pain in the form of spontaneous mental imagery, enabling insight into patients' personal experience (Berna, 2016). Berna reports that therapeutic interventions may be helpful in the form of positive guided imagery for pain relief. When art is produced regarding a health condition or experience, it can become a tool which enables an audience to experience empathy and understanding (Bucciarelli, 2016). It would be useful to explore the extent to which this is true in the case of chronic pain by examining audience responses to creative works about the condition, and the level to which they engage empathically with them.

Representations and interpretations

The term 'representation' is used to refer to how language and images create meaning about the world around us (Sturken & Cartwright, 2001). Not all representations need to be 'artefacts', for example mental representations are non-artefacts (Kulvicki, 2014), such as metaphors. In discussing creative representations of pain, it is important to consider the cultural and social context(s) in which they are both

produced and interpreted as these are mediated by ideology and subjectivity (Harrison, 2002). Whether ‘in the ‘art room’ or the ‘consulting room’’, writes Padfield (2011: 254), the social context in which the images are viewed affects their interpretation. Padfield has followed a semiotic⁴ approach to the analysis of images created in collaboration with people who have persistent pain. The images have multiple meanings due to the different readings of the signs in the pieces. Padfield argues that, in her development of a visual tool to be used between patient and clinician, the multiple interpretations are not significant as the emphasis is on the facilitation of communication and narrative (2011). Arguably, interpretations are shaped by who views and with what motivation, in what context or role they view, and with what knowledge or experience of chronic pain. Banks and Zeitlyn (2015) state that initial understandings or interpretations of images are frequently pre-scripted. Consequently, additional information on interpretations of images about living with pain would be useful for gaining insight to how these tools may be optimised in clinical settings.

The ‘Communicating Chronic Pain’ project, by Tarr et al., used arts workshops to explore non-verbal aspects of the persistent pain experience (Tarr et al., 2014). Speaking of her experience participating in the project, Sharon Jackson noted that the important achievement of the project was that ‘it communicates that chronic pain truly exists’ (Tarr et al., 2014: 15). This demonstrates the role that such creative activities can have in aiding the process of validating a person’s pain. Jackson goes on to note that prior to the workshop she had found it difficult to conceive how she could use an object and photography to represent her pain but ‘ultimately found it very valuable to represent my pain through photography’ (2014:17). This suggests that while there may be difficulties for some people to engage with the concept of representing pain creatively, in particular those without creative backgrounds, support and encouragement to do so can make it both possible and beneficial. However, not all

⁴ Semiotics is concerned with the use of ‘signs’ in culture to convey meaning and how these are interpreted (Hall, 1997)

experiences were so positive, as Kate Jolly describes her own experience in the project, stating that for those people with 'artistic prowess', legitimacy was secured, but for others their pain was devalued through the inability to produce something they deemed an accurate reflection of their experience (Tarr et al., 2014). Consequently, those people required 'reinforcement with textual explanation' (2014: 34), suggesting that there was a need for accompanying text to support the message of the artistic representation of a pain experience. Jolly's phrasing, that those without 'artistic prowess' required text to strengthen the message of their piece, implies a belief that text should not be required to aid understanding, or that it devalues the communicative value of the image itself.

Art is used as a method to gain understanding about persistent pain by Henare et al. (2003) who ask what the meaning of the condition is to those people experiencing it. Henare et al.'s method entailed asking participants, who were attending a pain management programme, to create a visual image of their pain and present a narrative/interview alongside it. The issue of interpretation is raised in passing as the authors note that their method allowed participants 'to explain their meanings rather than have their meanings determined by others' (Henare et al., 2003: 516). This certainly suggests that a reading of the image in the manner intended by the creator is likely. However, it does not provide insight on what interpretations audiences may construct by viewing the works or if the images create an empathic response, for example. Possibly it is through the elicitation of empathy that a person with pain may feel their creative work has been successful in portraying their experience. Additionally, the creator's meaning is unlikely to be the only possible interpretation as, through a postmodern perspective, different interpretations are individual, relative (Williams, 2016) and of equal value. It would be of interest to know if those creating the works agreed that multiple interpretations, or those differing from what they intended, were valid. In addition, as the images produced by Henare et al.'s participants were done so specifically for the research purpose they may be influenced in their depiction by an awareness of who would be looking at them. Consequently, it

would be helpful to explore if creative works created outside of research held specific intended meanings for those creating them (and those viewing them).

The ambiguity of images is reported by Padfield and Zakrzewska (2018) as helping to enable a more equal interaction within the clinical setting. The differing perspectives entailed in viewing the works require patients to describe in their own words their pain experience and what it means to them, in order to arrive at a shared understanding; doing so can provoke 'the co-creation of new ways of 'knowing' illness and pain' (2018: 216). The authors make a strong argument that at 'the intersection of pain, language and image' (2018: 222) new language can be born from patients' own worlds. Consequently, this may allow patients and clinicians to move forward in discussing 'management of pain in the context of that individual's life' (ibid.). It is clear, therefore, that there is evidence of the value of using creative images, in combination with language, to facilitate more effective communication between people with pain and others. This also has been shown to have the potential to address power imbalances within clinical encounters (Semino et al., 2017) which may aid the patient's sense of their pain being validated. While in Padfield's research multiple meanings or interpretations of images are not of concern, it is not known if artists who express their pain creatively feel the same way about their own works, or if it is important that their intended meaning be interpreted accurately. Published research which includes consideration of the interpretations of creative pieces about chronic pain, discussed by those who created the works and other audience members, has not been located.

Issues around interpretations of artworks are picked up Ignagni and Church (2008) who caution that, 'while an artistic format may capture and hold audience attention', little is known of 'how those audiences interpret the artwork' (2008: 630). They question how the use of artistic forms affect the content of the representation, noting that if unconventional it may 'force audiences to make their own sense of the content' (Ignagni & Church, 2008: 630). The authors' phrasing implies they do not deem it appropriate that audiences form their own understanding of artworks' meanings. This raises the matter of how audiences interpret works. Also, what value or role an

exhibition may have in communicating the experience of persistent pain through the display of creative representations, and understanding how audiences interpret such works. The social communication model of pain allows for a study of communications as interactions, and of correspondence between the message as intended and the message as interpreted (Craig, 2018). This leaves room for errors in communication (ibid.) so it may be helpful to have a greater understanding of how interpretations of creative communications of pain are constructed.

Meaning-making processes have been considered by Lomax and Fink (2010) through their work on the effects of collective viewing and context on the interpretation of images. Lomax and Fink (2010) warn that focussing primarily on the intentions of the producer of an image omits consideration of the multiple meanings of the work, as experienced by the audience(s). Doing so would also counter postmodern approaches of seeking multiple truths, rather than focusing on the creator's intended meaning. The impact of this is that it allows for considering how effectively a work communicates an experience of living with pain and if issues arise through the multiple meanings possible, as well as the differences from the creator's intended meaning. The nature of polysemic readings is important. Jewitt (2014) defines polysemic as the ability of a sign or feature (a painting or an element of one, for example) to have multiple meanings or interpretations, which accords with postmodern understandings of interpretation. Rose (2012) observes that meanings may vary for audiences according to age, gender, sexuality, and other traits; demonstrating the value of considering the demographics of who is viewing. It is possible that creative works are of a polysemic nature, holding a different meaning for each audience demographic. It would therefore be helpful to consider the influence of someone's experience with chronic pain on the meanings attributed to an artwork when viewing it. This emphasises the importance of considering an exhibit's interpreted meaning, in relation to the audience member's pain status.

Analysis of visual resources, notes Harrison (2002), may focus on the content presented, the message or purpose of the pieces, symbolism, or semiotics⁴. Harrison

argues that inviting participants to interpret images raises questions about 'how the worlds of self are distinguishable from others' (Harrison, 2002: 864), going on to note that 'audience' is an underdeveloped and problematic area of visual sociology. Consequently, there is a gap in knowledge concerning audience interpretations of images in the field of sociology and in particular relating to creative works about life with pain. Lomax and Fink (2010) argue that a method is needed that makes visible respondents' individual and collective responses to signs to show how multiple meanings may arise and be negotiated through interactions of audience members. Consequently, it would be interesting to capture the audience interactions themselves in order to consider their influences on the meanings constructed. Specifically, for example, whether someone with pain commenting first on a work would affect the responses which followed or subsequent interpretations, if the individual's pain status was known by other audience members. Such a negotiation of meaning-making could be enhanced through the contributions of creators to discussions. This would allow for an exploration of whether the creator may be deemed an 'authority' or to hold power in the negotiation of meaning. For example, whether their contributions led other audience members to concede to their interpretation. Alternatively, it may be that the creator renegotiates their own understanding of their work or pain.

A clinician, Kate Jolly, noted that when asked for an interpretation of a piece during the 'Communicating Chronic Pain' project, she felt threatened, 'as if an invasion of my person was taking place' (Tarr et al., 2014: 34). Jolly states that this may have been a wish not to share her pain or suffering with other people, and a belief that 'the piece should say it all' (ibid.), or may simply have been that she did not know how to explain herself. All of these observations demonstrate some of the complex issues in the the representation and interpretation of creative works, as well as the sense of pain as being a private experience which is difficult to make public.

Pain as public

While pain is a private and subjective experience, argues Craig (2018), there are almost 'inevitable public manifestations that permit others to infer painful experience' (2018: 35). Suggesting that there may be public displays of pain, perhaps without the knowledge of the individual concerned. Depending on the situation and past experiences, personality traits and affective state, the form of pain expression can vary substantially (Kunz, et al., 2018). Each form used to express pain (such as, facial expressions, body movements, posture, pain ratings and self-report) is able to capture certain aspects of the experience but is inadequate for the complex multidimensionality of pain (Kunz, et al., 2018). Craig (2018) argues that social norms lead to moderation of the verbal expression of pain, in order to be appropriate to the situation. However, nonverbal communication, such as facial expressions, tend to be more spontaneous (Craig, 2018: 36) and therefore less moderated in public. Kunz et al. (2018) note that the mutual influences between the subjective experience of pain and forms of expressing it work in parallel in responding to pain, rather than processing the sensation and the facial expression following after it. This is important in terms of considering the spontaneous expression of pain and the public-private display of the experience.

Social etiquette regarding the display of pain is learned at a young age, during childhood (Kunz, et al., 2018). Pain may be hidden in the presence of a stranger as expressing it might be interpreted as a sign of weakness and vulnerability. However, expressing it in the presence of loved ones may elicit support, demonstrating why some people wish to be able to communicate it more effectively than they feel they are achieving. Jackson (2005, cited in Birk, 2013: 394) notes that pain is doubly paradoxical as it is a quintessentially private experience dependent upon socially visible behaviour to make it real to others, yet that behaviour is likely to lead to suspicions about its validity. The use of 'props' (such as walking aids) is one way in which someone will publicly display their pain or impairment in order to be taken seriously, despite simultaneously wishing to appear healthy (Birk, 2013). Werner and Malterud (2003, cited in Birk, 2013) refer to this as 'credibility work'. In the process,

the individual's already limited energy resources are expended on trying to appear a 'credible patient' rather than on managing their pain (Birk, 2013).

Biro (2010) argues that it is possible to share, to some degree, experiences like pain which are considered to be private. He states that the public side of pain is more meaningful than an unshareable and private one. Biro argues,

Emphasizing the public side of pain can change the mindset of sufferers so that they no longer [...] resign themselves to dwell in pain alone (2010: 48)

Consequently, the implication is that it is not appropriate to keep talking about the absolute privacy of pain as the working language does imply some form of mutual understanding (Biro, discussing Wittgenstein, 2010: 50). Witnessing and responding to a person's pain means that it has been communicated and is accessible, thereby meaning it is, to some degree, public (Biro, 2010). Therefore, argues Biro, the only part of pain that is truly private is having the experience, or the pain as an event, as Bourke (2014) describes it. However, once language and meaning are present, the private experience of pain has entered the public realm through the sharing of it (Bourke, 2014). Biro (2010) encourages the belief that it is possible to share experiences of pain and to focus on the public and shareable aspects of it, rather than the private, helping to address the isolation people experience. This raises the issue of how someone should express the pain, if what Sheppard (2019) argues is correct regarding the difficulty of finding people willing to *listen* to the stories of pain. Biro (2010) has considered the various methods by which it may be possible for people to express their pain. I quote his words at length here because they demonstrate both the importance of expressing pain and the potential to do so via different mediums:

[Those with pain] must be able to give their experiences form and meaning in whatever medium they are comfortable with. If they can't find words, then perhaps they can make pictures. Either route allows them to escape the isolating epoché of pain. Expression inevitably leads to knowledge and community, and it may also work like medicine to less our pain, as my pictures did for me in the hospital (2010: 180).

Given the difficulties in sharing the private experience of pain, Biro states that it would be easy to not bother trying. However, he is arguing that pain is an inherent part of life and we should therefore try to share it, demonstrating support for the expression of pain in whatever medium works for the individual. Consequently, Biro is writing of his personal experience in finding pictures helpful while in hospital. Speaking of hers and others' participation in the 'Communicating Chronic Pain' arts workshops, Sharon Jackson notes that the experience led those present to speak of 'a shared experience of chronic pain' (Tarr et al., 2014: 18). Such shared experiences are noted by Newhouse et al. (2018) as an important part of feeling supported; speaking of sharing images, the authors state that this is 'particularly pertinent if the experiences that resonate come from people 'like you'' (2018: 144). It would be useful to explore this idea further to find whether others have the same experience using and sharing images, and if the making of creative representations is therapeutic or lessens the isolation for individuals struggling to share their pain experiences.

The invisibility and frequent diagnostic uncertainty surrounding chronic physical pain can create their own separate issues for the individual, as well as the physical impact itself. The invisibility adds an 'extra burden' to the individual, which, claims Gotlib (2013), forms a more serious threat to the person's identity than the condition itself. Scarry (1985) asserted that to have pain is to have certainty, but to see another's pain is to have doubt. This is partly because the only evidence for its existence is the expression of it (Davey & Seale, 2002), or 'performance' of 'abnormal illness behaviour' in an attempt to make visible the pain (Kenny, 2004: 303). Birk writes of wondering how to feel authentic 'when I always have to play-act my credibility for others?' (Birk, 2013: 395). These issues show that methods by which validation may be achieved are complex and that validation of pain experience is an issue internally for people as well as gaining it from others.

Validation is defined as 'confirmation, corroboration or substantiation' (Quintner & Cohen, 2016: 289). Without clear pathological evidence such confirmation is not possible. However, while it may not be possible to prove someone is in pain, it is also

impossible to prove they are not. As McCaffery wrote, 'Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does' (McCaffery, 1968, cited in Clarke & Iphofen, 2008). For the person with persistent pain, validation includes a need for recognition and affirmation by the clinician of what they are experiencing which can be achieved by stating 'I believe he is in pain', rather than 'he is in pain' (Quintner & Cohen, 2016: 281). Craig (2018) argues that a greater understanding of social factors influencing observer responses is needed, whether these are indifferent, empathic or provoke further distress. It would therefore be useful to explore further what responses witnesses to pain have and how these are influenced. For example, if personal experience of chronic pain influences reactions, if certain methods of expressing chronic pain affect responses and how empathic these are. It would also be helpful to explore if creative forms of expression may facilitate greater validation of the pain experience.

There is limited knowledge of what type of help is beneficial to people with musculoskeletal pain because multidisciplinary programs (which include exercise, relaxation, psychological and educational programs) evaluate outcomes rather than processes (Werner et al., 2003). As a result, knowledge is limited about what interventions are helpful, why and for whom. Thompson (2016) writes that there is plenty of published research concerning those people who find it difficult to adjust to life with chronic pain. However, there is less information available demonstrating the ways in which resilient people have adapted to their pain. While there is growing interest in the study of people who are living well with chronic pain, there is much more needed. Thompson states that this is particularly important in order to understand processes involved in coping, as

understanding the approaches used by people who remain resilient can shed light on aspects of coping that are not readily apparent when studying those who have more difficulty with their pain (2016: 319).

Wendell (1996, cited in Mintz, 2011) notes that following her adjustment to life with illness, her dominant struggles are no longer with the condition itself but 'primarily social and psycho-ethical' (1996: 3, cited in Mintz, 2011: 252). There is a need to show

that a person can 'live well' with pain but the emphasis upon biomedical language and frames of understanding can make this challenging. Arguably, this is a role that creative representations might have in demonstrating not only what can be produced but by creating a representation of a life with pain that may surprise viewers. It would also be interesting to know if creating works expressing pain experiences (and/or sharing them publicly) is one process which helps people to live well with their pain.

Over half of the works featured on the PAIN Exhibit website accord to a theme of communicating the personal experience of pain and Collen notes that there is an intention to give 'a voice' to those who have persistent pain (2005: 52). This supports the argument that not only is there potential for the chronic pain experience to be shared but also the desire for it to be. Daudet, for example, noted the 'joy at finding others who suffer as you do' (2002: 31-2). Through the sharing of personal pain experiences, research participants have been reported to value 'no longer being alone or misunderstood with their pain' (Henare, et al., 2003: 515). The benefits of sharing their works, for those artists featured on the PAIN Exhibit website, is not explored, and research examining the benefits of sharing creative representations of chronic pain online has not been carried out (to the best of my knowledge) through the experiences of those who created the works and those viewing the works. It would therefore be helpful to consider the possible benefits of this process for both groups (creators of works and audience members) to explore what, if any, correlations may be drawn in their experiences.

Empathy and validation

Discussing narratives of chronic pain relayed to him, Kugelmann (1997) states that patients desired

legitimation of their suffering. They wanted someone, especially someone with authority, namely a physician, to recognise their pain. They felt dismissed, they felt that there ought to be a visible sign that they are suffering (1997: 268)

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This raises the question of whether a creative representation (specifically a visual work, in the context of Kugelman's comments) would help to achieve this legitimisation and recognition and may act as a visible sign of the person's pain experiences.

People with chronic pain, observes Sheppard (2019), feel unable to speak of their pain and the related emotions. Research participants felt limited in the freedom to express emotion due to the stigma of doing so. Consequently, those people struggle to engage with pain sensations because 'having their pain recognised by others was an important part of coming to live with [it]' (Sheppard, 2019: 7). This accords with Ellingson (1998) who writes of the need for validation of experience,

I feel a powerful urge to be heard. When I tell my story and others' stories, I seek acknowledgment (from myself and others) of what we suffered (1998: 9).

Having pain go unrecognised or disbelieved impacts upon the sense of self for the person with pain (Sheppard, 2019), demonstrating the importance of validating one's experience.

Pain exists in moments, and the experience figuratively pauses time, but there is a need to capture these for later reference to aid someone in expressing those 'pain events' (Bourke, 2014). However, those with chronic pain also report reducing how much they talk about it with others, citing that people do not want to listen (as touched upon above) or that it is a subjective experience which other people cannot understand. This creates an inherent contradiction in wishing to be heard and for the pain experience to be recognised, but also feeling that their experience is personal and should remain private, or that the telling of it is unwelcome. Quayson (2007, cited in Mintz, 2011) refers to pain as an opportunity for 'empathetic repositioning' – when someone who does not have pain becomes witness to it, recognising and thus validating the experience of the person with pain (Mintz, 2011: 257). It is the need for empathy and validation of pain experiences to which I now turn.

Definitions of empathy differ but Goubert et al. (2005) define it in relation to pain as ‘a sense of knowing the experience of another person with cognitive, affective and behavioural components’ (2005: 285). Experiencing pain does not occur in a social vacuum, but rather, ‘within a rich social environment comprising individuals (both pain sufferers and observers)’ and each has their own goals or concerns (Vervoort & Trost, 2018: 58). Resonating with a person’s emotional state through empathic concern and affect sharing, while recognising that the person is in pain, enables empathy with someone’s experience of suffering (Giummarra et al., 2016). Empathy entails a recognition of an experience at an individual and personal level. As chronic pain is such a subjective experience, it follows that achieving empathy and feeling it has been achieved are also subjective. A starting point for empathy, suggests Rosen (2018), is to rekindle a person’s memory of moments of pain, to enable a connection with someone living with long-term pain. However, given the reluctance of people to hear of another person’s pain, as noted by Sheppard (2019) and others above, it is difficult to achieve this. It is therefore helpful to consider a range of ways in which empathy may be fostered.

In order for someone to be viewed as a person, as opposed to ‘just’ a patient with pain, a clinician needs to do more than consult the individual’s medical records (Hansson et al., 2016). Showing sensitivity towards the lifeworld in which a person’s pain is experienced, write Hansson et al. (2016), and having open person-centred communication with an empathically supportive manner, enables a stronger clinician-patient relationship. Demonstrating empathy and understanding in this way is effective in helping people with pain to feel that they are being taken seriously and believed (Hansson et al., 2016), which creates the sense that their experiences are being recognised.

Tremblay et al. (2018) note that most authors who discuss empathy make reference to ‘the capacity to perceive, understand, represent, and share, to a certain degree, someone else’s mental states and feelings’ (2018: 152). de la Vega et al. (2018) observe that demonstrating empathy toward others’ pain may help that person to feel

validated. As an actor for medical exams, Jamison (2014) writes of being provided with instructions regarding evaluating the students. The need to 'voice empathy' in a sympathetic manner was not sufficient, the right words were needed 'to get credit for compassion' (Jamison, 2014: 3). The emphasis upon the 'right words' is interesting as it demonstrates an understanding that, for patients, a sympathetic or understanding tone may not be sufficient to feel that their experiences are truly being understood or recognised.

Stigma and impression management

Linked to the difficulties in talking about and showing pain discussed above, is the issue of stigma, as touched upon in both the introduction and this chapter. The concept of stigma is associated most closely with Goffman (1963) who used it to refer to 'an attribute that is deeply discrediting' (1963: 13), and the relationship between that attribute and a stereotype, such as how someone 'normal' is characterised.

Goffman discusses the constant need for the stigmatised individual to calculate the impression being made, in a way that others do not. Applied to the individual living with chronic pain, there is a need, as discussed above, to manage the level to which pain is, or is not, visible to other people. This may include finding ways to show the pain, as well as to hide its impact. The impression management entailed links to Goffman's discussion of the presentation of self (1959), through which a person performs the 'self' they wish to present to a particular audience. Goffman draws on theatrical concepts of frontstage and backstage to discuss the public and private portrayals of self and the performance entailed. The self presented to others tends to exemplify the accepted, non-stigmatised, values of society (as far as possible).

Difficulties managing the performance ensue if someone encounters a portrayal that was not meant for them; for example, accidentally encountering the 'backstage' persona. This may be the case when managing the visible performance of pain, or, equally, in hiding the impact of pain on the individual from those around. Goffman notes that where the differentness of a person may not be known by others, or visible, they have the decision of whether to reveal this 'failing' and 'to whom, how, when,

and where' (Goffman, 1963: 57). Such potentially undisclosed information allows the person to 'pass' as 'normal' (1963). Goffman (1981) notes that audiences (of a podium speech) will hear something in a way that is special to them, demonstrating the subjectivity entailed in the interpretation and understanding of any form of communication or performance. Consequently, this may heighten problems associated with credibility, being thought to exaggerate or fake the pain experienced, and may increase associated stigma.

Expectations regarding appropriate behaviour when ill are linked to 'our unique biographies' (Kleinman, 1988: 5). However, as an individual consists of a 'multiplicity of selves' (Goffman, 1963: 81), there may be no single linear biography (in keeping with Franks' (1995) idea of a chaos narrative having no clear trajectory); thus, a person with chronic pain may have no single understanding of what behaviour is appropriate at a given time. Goffman (1963) notes that, socially, these multiple selves can enable careful management of role and audience, enabling the maintenance of different selves. For example, performing the role of someone with a stigmatised, undesirable trait (such as chronic pain) or of someone 'passing' as 'normal'. Linked to impression management is the emotion work involved in managing one's own performance and the responses of others to this.

Emotion work

Managing one's own, and other peoples', responses to an individual's pain entails emotion work. Discussing the management of emotions, Hochschild (2012 [1983]) notes that there are three discourses to consider, those of labour, display and emotion. As may be expected by its name, the first discourse of labour relates to emotions in a work or organisational context. The second concerns the display of feeling in a more personal manner than the first discourse. The display of emotions relates to Goffman's (1959) presentation of self and the impression management people engage in frontstage and backstage, or in public and in private. Emotion, as the third discourse discussed by Hochschild (2012 [1983]), relates to the nature of emotion and how to manage it. Such emotion management is a private act, influenced by what

is considered appropriate to feel and express (Wharton, 2009). Emotion work can be carried out 'by the self upon the self, by the self upon others, and by others upon oneself' (Hochschild, 1979: 562), in accordance with the demands of a given social situation (Bendelow, 2009). Ongoing emotion work in self-presentation may create chronic 'dramaturgical' stress (Bendelow, 2009), linked to the effort involved in 'passing' (Goffman, 1963). This increases the likelihood that a 'self' intended for public or frontstage audiences may slip, leading to an audience accidentally encountering a person's private self (such as the undisguised self struggling with chronic pain in a given moment).

Conclusion

The literature presented above demonstrates that there is an ability for people with pain to express their experiences, though this may be limited and experienced as difficult to do so effectively, due to fears regarding stigmatisation, among other things. There are also challenges associated with hearing about pain, and a reluctance to do so. A limited understanding as to how best to describe pain is implied because attempts to do so are experienced as insufficient, although language may be prolific and the body is utilised through co-speech gestures. Arguments have been demonstrated which promote the creative use of language and of visual metaphors in art to express pain experiences and provide more effective communication between a person with pain and others. However, a gap in research knowledge has been identified concerning audience constructed meanings of creative works about pain. This might address the concern of what is lost by focusing only on the creators' intention when producing a work. The potential value of communicating chronic pain creatively may be demonstrated by examining the multiple interpretations of works. In relation to pain this is of value in understanding the meaning-making processes connected to the condition, by both those who live with it and those who do not have the condition. The seeking of empathy, validation and someone to hear about persistent pain have all been shown to be points of importance to people living with

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pain and so it is of interest to consider how creativity may be used to help address these issues.

Chapter Three: Method and methodology

Introduction

This chapter details the research design, beginning with a demonstration of the development of the research questions, design of data collection and process of data analysis. Justification for the application of postmodernism as the underlying epistemology to the research design is provided. The research method of online exhibitions, hosted on two social media platforms, Facebook and WordPress, will be described. The exhibitions were used to generate questionnaire responses (in WordPress) and asynchronous focus group discussion data (through a Facebook group). The method design and data generated will be discussed alongside the challenges posed by its unusual characteristics. The decision for this method of research will be contextualised through discussion of relevant literature and by showing the development of the research questions, which I turn to first.

Research Questions

The development of the research questions is demonstrated in Figure 2, p. 49. These occurred through a process of thinking about the broad area of interest and narrowing this down to specific items (Bryman, 2008: 71). It illustrates that the topic of the thesis arose out of my interest in the potential of creativity to produce an illness narrative when language is proving insufficient for someone with persistent pain. The literature review demonstrates that there is a small but growing body of research linked to the health of people involved in arts and crafts projects (for example, see Angheluta and Lee, 2011; Clift, 2011; Fraser and Sayah, 2011; Reynolds, 2002). There is presently a significant gap in the field concerning knowledge about those people with chronic pain who participate in arts and crafts activities. Although it is beginning to be addressed, there is a gap in research regarding the use of creative activities for the expression of pain, rather than for therapy or research purposes.

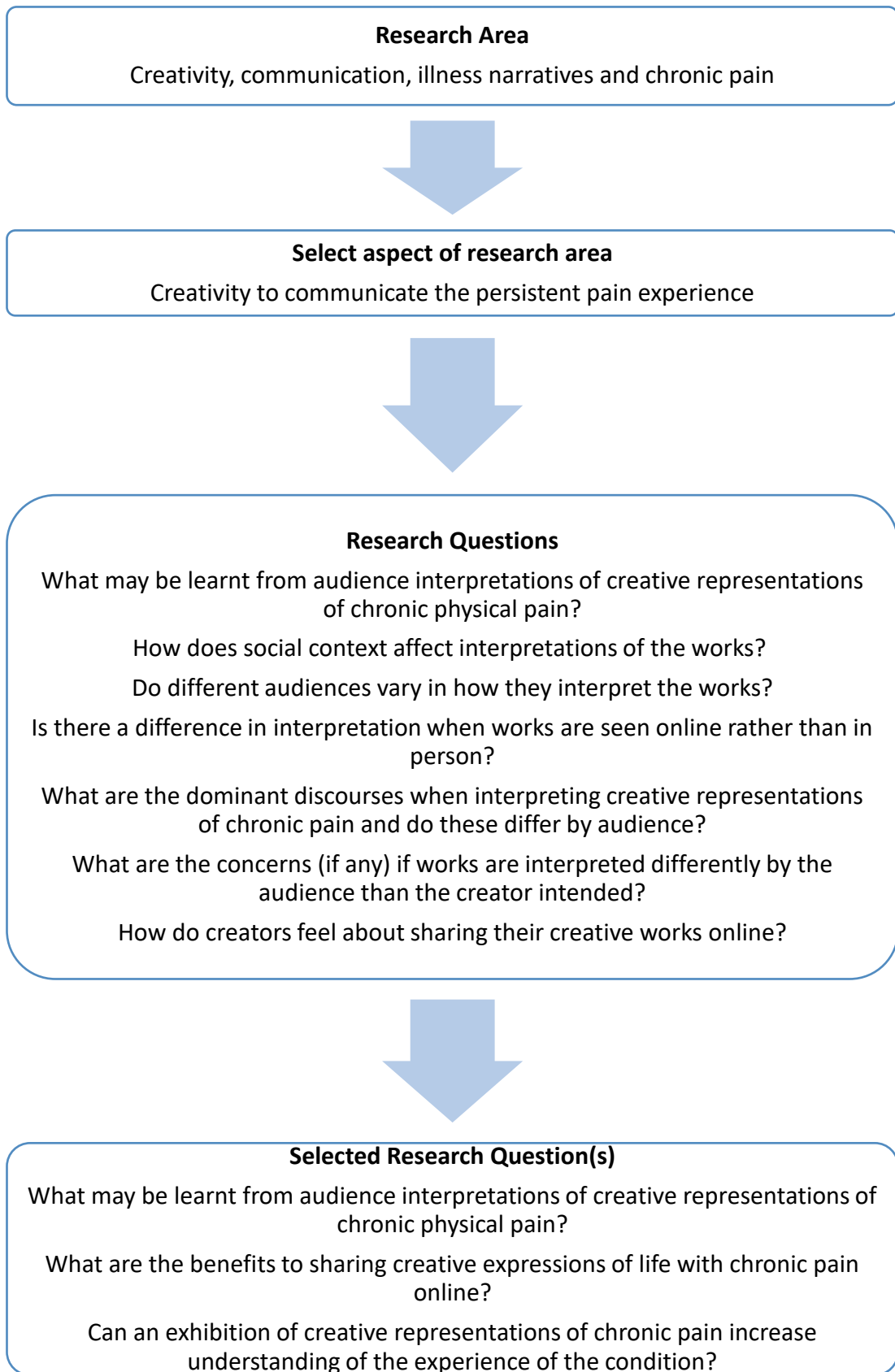


Figure 2 Development of Research Questions

Gaps identified in the literature review generated the set of research questions visible in box three of Figure 2. These were refined, with the aid of further reading and reflection, to those in the final box of Figure 2:

1. What may be learnt from audience interpretations of creative representations of chronic physical pain?
2. What are the benefits to sharing creative expressions of life with chronic pain online?
3. Can an exhibition of creative representations of chronic pain increase understanding of the experience of the condition?

In accordance with Lewis (2003), these questions are focused but not too narrow and can feasibly be researched through the collection of data; they are also clear and intelligible. In addition, the issues raised by the questions are relevant and useful to both pain management practice and the research field.

Addressing these questions will increase knowledge about the potential of using artistic and creative approaches to express the experience of living with chronic pain. This is important in order to consider techniques for broadening communication methods of the invisible condition. The use of an exhibition, as a method of communicating the experience of life with chronic pain, is valuable to gain insight into ways to raise public awareness. Additionally, using exhibitions will explore alternative techniques to share the chronic pain experience with others, enabling the person with pain to feel that they are receiving validation. Additionally, the research questions are focussed on exploring the interpretations and audience responses to works through the process of viewing creative depictions online. The use of an exhibition as a tool to collect research data is also considered in the process of addressing these questions, contributing new knowledge to the field of research methods.

Epistemological approach of postmodernism

The meaning of the term 'postmodernism' is contested, being referred to as a 'moment', 'condition', 'style' or historical 'period' (Hutcheon, 2013). Noting that postmodernism is easier to recognise than define, Gray (1999) observes that it is characterised by relativism and a lack of objective facts. This is because reality has a plurality of meanings contingent upon the individual. Williams (2016) describes postmodernism as a movement; he notes that it

rejects the certainty of scientific, or objective, efforts to explain reality and instead focuses on the relative truths or experiences of individuals or groups (2016: 165).

Williams adds that there is an inherent irony in attempting to define what postmodernism is, given that it rejects the idea of totalising theories or unified systems of thought (known as 'meta-narratives') (Williams, 2016: 167). As a way of thinking, writes Hutcheon (2013: 121), postmodernism is characterised by a 'both/and kind of logic,' as opposed to binary 'either/or' type oppositions. This is congruent with philosopher Derrida's approach of deconstruction which sought to break down the hierarchical values encompassed in binaries (Hutcheon, 2013). Lyotard argued that instead of a single truth, there are multiple truths which, he stated, caused a crisis of legitimation (Lyotard, 1984, cited in Hutcheon, 2013). This shift to focus on multiple truths (as opposed to 'grand' or 'meta-narratives' of a universal truth, based on one particular culture or scientific theory, which are rejected under postmodernist approaches) led to a new focus on those previously ignored or excluded (Hutcheon, 2013). In the case of people living with chronic pain, such multiple truths are seen through the individual and subjective nature of the condition, both how it manifests and the impact it has on the self.

Sim (2011) states that postmodernism entails embracing scepticism about what culture stands for. While Hesselink and Schatman (2018) write that this scepticism extends to a questioning of scientific and evidence-based knowledge, in a rejection of Enlightenment reasoning, objectivity and rationality. In relation to pain medicine, Hesselink and Schatman note that postmodernism has led to the opinion of the patient

having the same validity as empirical data (2018), each being one narrative and of equal value. The authors warn of implications in the treatment of patients as they rely upon word-of-mouth anecdotal evidence to request particular prescriptions (for which there may or may not be supportive clinical evidence), deeming this advice to be of equal value to medical evidence. Hesselink and Schatman express concern for the importance of maintaining constructive communication and relationships between patients and healthcare professionals under these circumstances. They add that 'ideally' postmodern pain medicine would be 'cured', arguing a need to be 'content with encouraging a shared decision-making model' (Hesselink & Schatman, 2018: 2850). This implies that a biomedical model would be preferred by Hesselink and Schatman, allowing the clinician to prescribe what they perceive to be the best treatment. However, Gray (1999) argues that the number of patients wishing to be in charge of their health decisions means that the standard approach should be 'empowerment rather than paternalism' (1999: 1552).

Successful communication and a consultative style that involves and empowers patients is increasingly recognised as improving the patient's satisfaction and their clinical outcome (Gray, 1999). As such, strengthening the bond between clinician and patient may provide a therapeutic effect and this might be achieved through hearing the patient's narrative (ibid.), linking to established ideas regarding the benefits of narrative medicine (for example, Charon, 2006; Greenhalgh and Hurwitz, 1998). Gray notes that an adaption to a postmodern environment includes the empowerment of patients (1999). This is due to the nature of postmodernism which demonstrates disdain for authority and wisdom (Sim, 2011b) and enables the voices of those previously ignored or othered to be recognised.

In postmodernism, meanings are 'imposed and arbitrary,' leading to a lack of scientific truth (Williams, 2016). However, Williams writes that 'affirmative' postmodern approaches embrace relativism but also do not reject research that describes or interprets (2016: 166). As postmodernism sees all realities as socially constructed, so are the interpretations of those constructed realities. Following the deconstructivist

approach of Derrida (1978, cited in Williams, 2016), the 'text' (or, in this research, the creative work exhibited) is central, rather than the author (creator) in postmodernism. Consequently, interpretations of creative works are relative and provide no information about reality beyond the work itself (Williams, 2016). Hutcheon (2013) notes that postmodern representations of ourselves do not reflect us and our world; rather, they enable meaning and value to be applied to both. Such meaning is never single, authentic or homogenous but plural, hybrid and shifting, therefore 'inviting collaboration with the reader' (or viewer, in the case of visual art) (Hutcheon, 2013: 127).

The concept of a collaborative meaning being constructed between creator and reader/viewer is pertinent when considering the interpretations of creative works expressing personal experiences of life with chronic pain. This also raises the concern of whether there is a 'correct' interpretation or meaning to be attached to the works, as demonstrated through the research question in box 3 of Figure 2, 'What are the concerns (if any) if works are interpreted differently by the audience than the creator intended?' As postmodernism argues that there are no 'true' or single interpretations of a work (just as there is not singular definition of pain, (Carr, 2018: S53)) it is important to understand the responses of creators if the audience interpretation differs from the meaning they wished to communicate (if there was a specific meaning or message in the work).

In pain medicine, as in healthcare more broadly, it is necessary to balance the need to recognise the autonomy of the individual and treatment plans they wish to pursue, with the evidence-based advice (Hesselink & Schatman, 2018). Postmodern pain education has created a shift from primarily biological understandings (such as nociceptors or subcellular processes) towards a broader range of evidence, including 'multiple types of knowledge, attitudes and experience including patient narratives' (Carr, 2018: S49). Allowing the voice of the person with pain to be heard as equal enables a recognition and validation of their opinion and experience. This can facilitate a more positive outcome for the individual. The research here considers the role that

creative methods may have in enabling an improved communication between clinician and patient.

Reality is reframed under postmodernism as turbulent and unpredictable, as opposed to the previously idealised view of it as unchanging (Carr, 2018). This is in keeping with the nature of living with chronic pain which fluctuates and may itself be described as 'turbulent and unpredictable.' Given that persistent pain is a subjective and individually experienced condition, it is appropriate that an epistemological approach is used which allows for the relative nature of those individual experiences, and which understands that the meanings attached hold significance for one person but may not be applied as a universal truth.

Developing the research design

Development of the research topic and specific questions is shown above in Figure 2. As will be discussed throughout this thesis, and most especially in Chapter Four 'The Pained Researcher', my personal experiences inevitably shape elements of this research (in its development, content and the data analysis) and are used to contribute insights. In keeping with this, my academic background has played a role in the development of the method chosen to explore the research questions. As my background includes Museum Studies, with research into the representation of disabled people in museum displays, my interest was sparked in how exhibitions may be used to both share the experience of living with pain and to collect research data. Consequently, my wider reading, together with the research questions, evolved to consider the interpretation of creative representations of pain, with a particular interest in how an exhibition may facilitate this.

The development of a research question surrounding the use of exhibitions to share creative works of chronic pain, led me to explore the feasibility of creating traditional physical exhibitions in gallery spaces. As shown by the question in box 3 of Figure 2

above, 'How does social context affect the interpretations of the works?', I was interested in how the interpretation of pieces may be affected by context (both physical location and the demographic details of who is viewing the work). As Gazi (2014) states, space impacts upon the construction of meaning, not only of the works exhibited but the cultures represented (or, in this instance, the condition of chronic pain). Therefore, I explored different options for physical exhibitions, such as considering the use of local community spaces, formal galleries with spaces to let and hospitals.

Contact was made with the local Arts for Health⁵ director (Arts for Health MK, n.d.), Sharon Paulger. Sharon was kind enough to meet to discuss my research topic and told me more about her work. Arts for Health (MK) runs various 'arts on prescription' programmes as well as a changing exhibition programme in MK Hospital (Arts for Health MK, n.d.). Additionally, a chronic pain psychologist (Dr. Peacock) at MK hospital is supportive of the Arts for Health scheme and Sharon's work. This raised the possibility of accessing the pain management department at MK hospital, if this became pertinent to the research, as well as to some of the exhibition space in the building. I explored some physical space options for exhibitions which would then be moved to different locations, to compare the interpretations and feedback for any responses potentially shaped by location.

The spaces available in MK hospital were in busy corridors that may make reflective consideration of the works difficult. Additionally, it was not possible to use the space near the pain clinic for temporary exhibitions, plus it was frequently very busy, with restricted space. When considering community spaces, Sinding et al. (2008) note that these may carry expectations of what will (and will not) be shown there, observing that 'the intersection of art, audience, and venue is an ethically complex space' (2008: 7).

5 'Arts for Health' and 'Arts on Prescription' programmes grew out of the Department of Health's commissioning of a project examining the role of the arts on healthcare settings in 2005

Upon further consideration, I felt that the use of physical exhibitions bore many logistical issues in terms of marketing multiple exhibitions, moving, handling, and storing items securely and safely, displaying them appropriately, together with the financial considerations of some hired spaces. There was also a concern over sourcing enough works that could be transported to the sites. Consequently, I felt it prudent to pursue online methods for the exhibitions and research method. As it transpired this was a valuable decision regarding the sourcing of works and audiences. It was also important as some participants appreciated being able to reflect on works in their own time, often leaving and returning to them at another time, as discussed in the findings, Chapters Six and Seven.

Exhibition as method

The appropriateness of the use of creativity and the visual to represent chronic physical pain has been demonstrated in the literature review (Chapter Two). The method used for data collection in the research for this thesis also enables the exploration of the potential for exhibitions to be used as a data collection method. First, it is appropriate to clarify how this research study, *Exhibiting Pain*, differs from the PAIN Exhibit site which has been mentioned previously in Chapter Two's literature review.

PAIN Exhibit is a website established in 2012 by former CEO, Mark Collen (PAIN Exhibit, Inc., n.d.). The site was created in order to use artworks as a way to raise awareness and understanding about chronic pain, and to give a voice to those living with it. In naming the galleries for this study I have drawn on the verb 'exhibiting' to emphasise this aspect of the research data collection technique and because of the way in which people often feel they must actively exhibit their pain for it be recognised (Main, In Press). In addition, PAIN Exhibit was not created for research purposes. Collen took on a greater curatorial role in the exhibiting of works, arranging these by theme, for example 'Suffering', 'Portraits of Pain' and 'Healthcare', among others. However, I have intentionally taken a minimal curatorial role for *Exhibiting Pain*, as discussed

below in sub-section 'Curatorial decisions', and I was also interested in featuring pieces outside of visual artworks. For example, I had hoped to include poetry, sound or music.

As noted in the literature review, there is an oversight in existing research regarding the use of exhibitions as a means to provide structured exhibition opportunities for people wishing to show works relating to their health. Consequently, creators' responses to participating in *Exhibiting Pain* were collected. The findings from analysing these may help to inform future practice about the potential benefits of exhibiting created works (whether of physical chronic pain or relating to another topic).

Hosting the exhibitions – choice of social media

As described above, initial development of ideas entailed the use of multiple physical exhibition spaces (to explore the influence of different contexts on interpretations) which would have provided an exciting way to generate data for this project, while exploring the impact of viewing in different physical spaces (for example, in a hospital, community space or public gallery). Drawing on personal experience of co-curating a public exhibition, the feasibility of using multiple physical display spaces proved unrealistic for logistical reasons (such as gaining access to exhibition spaces, storing, transporting and insuring the pieces and display restrictions). As an alternative, online exhibitions were chosen given that they enable a range of different formats to be included, avoiding many logistical difficulties and enabling a global audience to be reached.

Merolli et al. (2015) present statistics, from an online survey of people with persistent pain, of the outcomes and therapeutic affordances of using social media. Data gathered demonstrated that social network sites (such as Facebook and Twitter) are used by 90% of the respondents, while discussion forums and blogs are used by 48% and 44% of respondents respectively. This suggests that there is the potential to reach this demographic of audience via online methods of research, hosted in social media

applications. Additionally, results show that respondents experience therapeutic value in learning from others' experiences (of living with pain) via social network sites, discussion forums and blogs (91%, 92%, and 94% respondents respectively). Although this data is skewed because it is recording the responses of those people with chronic pain who are already using social media, it does suggest that this may be an accessible route to carry out research with people who might be restricted to physically accessing certain locations. Using online methods enables flexibility to accord with flares of chronic pain and is therefore appropriate to the demographic. However, further research carried out on these platforms would be helpful to assess to what extent people found it a helpful way to participate and share experiences.

Online research methods have the potential to create a sampling bias as they may exclude those people who do not use the internet or may not have regular access to it (unless they were recruited through non-internet-based promotion and had support to access the sites). Although the widespread availability of the internet (for example, in libraries, cafes and free Wi-Fi hotspots) and the proliferation of smartphones reduces the concern about audience access in online research, this is not resolved. However, Tate et al. (2009) address this issue in their work, which used online focus groups, by noting that, like traditional face-to-face focus groups, the intention of the study was to deepen knowledge rather than produce generalisable findings. It is appropriate to consider what is understood as 'generalisable'. I agree with Lewis and Ritchie (2003) who state that one concept (of three) by which generalisation may be understood is as 'theoretical'; whereby theoretical propositions or principles are drawn from a study for more general application. Consequently, while a sample may have an inherent bias, this will not automatically invalidate the findings of research carried out using online methods, or reduce their relevance.

Managing an online group, Corkhill (2012a) found that members of Stitchlinks (a therapeutic online knitting group) took some time to build enough confidence to participate. Questions were posted into Levine et al.'s (2011) MySpace (another social media site) research project, at a rate of 1-2 per day, with the project taking place over

seven days. However, Kenny (2005) argues that it is possible to maintain an online focus group over a longer period of time, having done so over eight weeks. Mayne's (2015a) Woolly Wellbeing Research Group had 394 members in October 2015. An infographic created in early April 2015 showed that the group had been running for approximately two months and had 324 members, showing an increase of 70 members over the interim period (Mayne, 2015b). It is unknown whether the group was still being actively promoted by Mayne though as this may have affected the rate of recruitment. The infographic illustrates that over the first two months 216 posts had been made and 1403 comments (comments are responses to textual, photographic, video, or shared link posts). This data shows activity and uptake in the research group, demonstrating the potential for a Facebook group to be used to carry out a research study.

Hosting the exhibitions on websites utilising Web 2.0 applications was free of charge and easily accessible to me. Additionally, it was felt that a substantial number of audience members would have experience in accessing such sites or similar. 'Web 2.0' is a term used to encompass, among other things, user generated activity such as social media pages (for example, Facebook, MySpace, Twitter), web-logs [blogs] (such as WordPress) and wikis (for example, Wikipedia) (Anderson, 2007). This research utilised a social media/networking site (Facebook) and a blog (WordPress).

Facebook has such a large number of users that I felt its use to host the exhibition would encourage people to participate as it may feel more familiar and convenient to those already using the site (in 2015, the milestone was reached of 1 billion users logging in on one day (BBC, 2015)). However, I also believed that a blog page may appeal to those people who do not use Facebook or who prefer to view the works through a more anonymous format, not needing to join the *Exhibiting Pain* closed

group⁶ on Facebook. A blog was an appropriate means through which to carry out this research as the process of commenting in response to posts (uploaded text, images or other information) is inherent to its nature. As such it was an appropriate means to collect data relating to how audiences interpret and respond to creative works (of life with pain). Blogs commonly become a conversation between participants, communicated to unlimited numbers of readers/viewers (Anderson, 2007). Yeo (2014) notes that a blog is 'an excellent application for any online exhibition projects' (Yeo, 2014: 108), noting that WordPress.com has an 'easy-to-use interface' (2014: 104). The decision to use the specific blog site WordPress⁷ was influenced largely through my familiarity with the software, thus reducing the time needed to become acquainted with the functions of the site, including the data that it records about activity on the pages. In addition, WordPress is an 'open source' form of software (WordPress, n.d. a), meaning that it is a community project, not requiring a fee and 'public spirited' by nature (Anderson, 2007). This accords with the nature of the exhibitions which were intended to enable people to feel their experience of living with chronic pain was recognised by more people, as well as being for research intended to increase knowledge concerning the creative communication of life with persistent pain.

Both Facebook and WordPress allow for comments to be made in response to individual posts, whether these are images of artworks, pieces of text, audio files or videos, as all of these formats can also be shared in both contexts. A conversation can develop on Facebook (WordPress follows a similar format) so that individual comments can be responded to, creating something of a conversation 'tree' or 'hierarchy'. The value of this was to explore how different comments may provoke specific responses or discussions, away from other comments made on the same posting or creative work, enabling multiple discussions to occur should participants wish. Using two different forms of software enabled me to reach a broad audience.

⁶ A 'closed group' on Facebook works like a private forum and only people who are members can see the content. However, anyone can search for the group and request to become a member (unless 'blocked' to prevent contact) (Moreau, 2019).

⁷ Other blog sites include, for example, Wix, Tumblr, Blogger, Weebly

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The use of the same works in both exhibitions helped to retain consistency, though creators were given the choice to exhibit in either gallery or both. Both sites presented the works, and comments, in slightly different formats (please see Appendix iii: Screenshots of the galleries for screenshots of the two galleries to demonstrate the differences), leading to different styles of audience feedback. The use of these methods for collecting data is discussed and evaluated below, in sub-section 'Data Collection,' and in the final chapter, sub-section 'Reflections on the method'.

Given that many people who experience chronic pain become restricted in both physical and social activities, the online nature of the research was appropriate as it assisted the inclusion of this otherwise hard-to-reach population. The use of this method helps to address gaps in the research field (demonstrated in Chapter Two's literature review) through the use of social media for hosting exhibitions, social media as a means through which to collect purposeful data (rather than using existing content for analysis, such as ethnographic research), the use of exhibitions as a research data collection tool and the use of social media to host exhibitions in a research context.

Asynchronous forum discussions

The manner in which online discussion areas are moderated has a bearing on the culture created within them (Thrul et al., 2017). Consequently, the nature of my online 'presence' was important to consider, as this could affect the atmosphere of the group, whether people wished to comment or even remain as members. It is important to ensure that a moderator does not dominate discussion but also helps to keep the space active and participants engaged. However, conducting focus groups online entails numerous advantages, including convenience for the participants (Levine, et al., 2011) and often the moderator.

Williams et al. (2012) note that asynchronous discussion forums reduce temporal restrictions, such as time-zones and work schedules, for both the participants and for

me as researcher. Additionally, in relation to this study, they were suitable because they enabled people to contribute when pain levels enabled them to do so. Such forums also provide the participants with time for reflection before responding to questions. While this has the limitation of removing spontaneous responses, it has the potential to aid the confidence of participants in contributing. This is partly because they have time to formulate their responses but also because they may be less self-conscious in an online environment, as supported by Williams et al. (2012) and Joinson (2001). An additional benefit to this sense of anonymity or distance is that it can lead to greater candour by participants, potentially creating richer data (Williams et al., 2012). The richness of data is supported by Wood and Griffiths (2007) who note that forums are an 'excellent source of rich textual material' with the benefit of being 'naturalistic' (2007: 159).

The asynchronous nature of the discussion reduces the effects of some accessibility issues that may slow proceedings in a synchronous online environment (for example, screen readers or slow typing speeds). Although there is reliance upon English literacy in order to participate in the discussions, Tanis (2007, cited in Williams et al., 2012) argues that it opens up communication for those people who struggle to express themselves verbally. Additionally, the increase in daily use of technologies that consist of written messages (such as text messaging, instant messaging applications, email and social media) has led to this now being a preferred means of communication for many people (Turkle, 2011, cited in Williams et al., 2012).

Recruitment of creative works

The recruitment of creators and of audience members meant that there was a two-fold process involved in recruiting participants. This process and the creation of the two galleries is described below, first by the recruitment of creators and the intricacies entailed. I then detail the creation of the galleries as this was the next step in the method process, followed by the launch of galleries and recruitment of audience

members. The data collection process is discussed separately for each gallery site as these entailed differing methods and challenges to be overcome.

The risk with online methods is that the sample will be inherently restricted to those with digital access and abilities. Conducting the research in English also restricts access for those with knowledge of the language (Mayne, 2017), although Facebook does now include a 'translation' option in its posts which will potentially help to overcome this in future research using the platform. Consequently, though in principle online methods enables a global reach, there are still some biases to the creator and audience samples recruited for *Exhibiting Pain*.

Recruiting participants for this project happened in two waves as the creators and exhibits needed to be obtained before data collection could begin. I return below to the recruitment of audience participants, for the data collection stage. It was my intention that the representations of chronic physical pain displayed would be volunteered by their creators, in response to promotion of the research, and would therefore be self-selecting. Gonzalez-Polledo and Tarr (2014) performed an analysis of pain images available on social media, following the rationale that if the image was publicly 'tagged'⁸, it was intended to be searchable and viewed publicly. While some images may be identified through online searches, I did not feel that it would be appropriate to use these in a research-led exhibition without consent from the creator (even when the works were free from copyright concerns). Additionally, my selection of images (unless following a strict and transparent process) may have created bias in the sample exhibited. I also wished to optimise the potential of this project to give voice to people with pain through the exhibition of their representations, given the difficulties people find in having the opportunity to express their pain publicly, as

⁸ A 'tag' is a phrase or word that can be assigned to some form of media (for example, photo, comments or videos) to organise or access them easily. It can also be a way to link online content to another person (Nations, 2017). For example, adding a tag of chronic pain art' to a photo will enable people searching for items with those content to find it easily.

demonstrated in the literature. Consequently, the research exhibitions were promoted to recruit creators and their works; this constitutes ‘found images/works’ in the field of visual research. They are classed as ‘found’ in that they were not created for the purposes of this research, they existed prior to and separate from the research (Mannay, 2016).

Mark Collen, former CEO of PAIN Exhibit, kindly sent promotional details to the artists who feature on the website, adding his own email to introduce me, mentioning that he intended to feature his work in the research also (Collen, 2016). I had first contacted Mark in 2013 when completing my MSc Health Research dissertation which focussed upon the works on the PAIN Exhibit website (Main, 2013). His support, by contacting the artists featured in PAIN Exhibit, was instrumental in establishing the *Exhibiting Pain* galleries. Additionally, relevant organisations were identified using online search methods and snowballing techniques, together with drawing on known organisations to request promotion of the research. This entailed searches via Google, on Twitter and in Facebook using key terms, for example ‘arts health organisation’, ‘pain art’ and ‘Chronic pain’, then contacting with details of the research and an invitation to participate. It was stated that I was looking for creative representations, whether visual arts, poetry, sound or other. The organisations were from a range of fields, such as those working specifically in pain management or charities targeting pain support, organisations and charities linked to particular medical conditions which entail long-term pain or support disabled people, Arts for Health organisations and practitioners, arts and crafts groups, allied health professionals and medics, and academic groups. Some creators were recruited through snowball and convenience methods, such as through prior contacts. It was appropriate to use a largely online and social media-based promotion given that this would help to capture an audience already accustomed to using such means of communication and therefore more likely to wish to participate through Facebook and/or WordPress. A promotional article was also featured in the magazine, *Pain Matters*, published by a chronic pain support charity, Pain Concern.

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Creators emailed or messaged (via Facebook instant messaging service) in response to the promotion of the research. The first email from most people included the completed consent form and details about their work(s). This was particularly the case for those responding to Mark Collen's contact. Until Mark sent his email, I had received three responses from creators and some others had expressed an interest in possibly participating. With Mark's help I received an influx of creators happy to contribute their work(s) within a few days of them receiving his email. Of the works featured in the exhibitions, 70% (16 creators) were a direct result of Mark Collen's promotion of the exhibition to the artists on his site (two were through me directly – including Mark himself, three from promotion via Facebook groups and two creators got in touch following a tweet by a fellow PhD researcher in the field of chronic pain). Potentially this sampling technique created a bias in the works featured as PAIN Exhibit is a visual art exhibition. However, the emphasis on visual artworks in *Exhibiting Pain* may also be a result of other sampling techniques and/or potentially the nature of choosing to represent pain creatively, perhaps in response to a difficulty finding appropriate words and therefore moving more to visual approaches. I was unable to recruit works in other mediums, such as audio/music pieces or poetry, although poets and those producing prose as 'stream of consciousness' have since shared works in the Facebook group and one features in the original gallery of works. However, it is possible that the use of the word 'Exhibiting,' and making reference to 'galleries,' in the promotional materials may have caused those who use non-visual art methods of representation to feel their work was not sought.

The inclusion criteria for works to be accepted for display included that they had been designed and/or created by a person who experiences persistent physical pain. While this may co-exist with emotional, mental, or social pain, the focus is on representations relating to the experience of living with chronic *physical* pain so it was instrumental that the creator fitted that criteria. This meant that when I received a work from someone featured on the PAIN Exhibit site I had to query with the creator if they have chronic physical pain because the questionnaire linked to the consent form suggested this was not the case. As it transpired, the individual has a physical condition resulting

from mental and emotional pain. It was necessary but difficult for me to return to the person and explain that I was unable to accept the work for the data collection period but would still be happy to upload it afterwards if they wished. This was a very difficult response to give as it seemed to imply that their pain was not suitable, real or relevant. Thankfully, the creator was very understanding and continued to be supportive of the project.

Online exhibitions enabled a wide range of mediums to be presented, reducing possible restrictions on admissible works, such as large sculptures or audio pieces, that may not have been suitable for some physical exhibition spaces, as discussed above. It was important to have good quality image reproductions of works which are visual but not created through electronic means, for example, of sculptures or paintings. Thus, an image needed to be of high enough resolution to be good quality but the file size not so large that it would be slow to load (WordPress, n.d. b). Fortunately, this did not prove to be a concern with any of the images received. On the contrary, higher resolution images had to be obtained for some of the promotional materials, such as for the article featured in the charity Pain Concern's magazine *Pain Matters*. Contacts were recorded in an Excel Spreadsheet, together with details of how the person was reached, dates contacted, responses received, title of work, decision about watermark, follow up required (for example, when waiting for an image or consent form) and other related information.

Constructing the galleries

I carried out the construction of the Facebook and WordPress exhibitions myself. Guidelines were followed to ensure as great accessibility as possible (Kelly, et al., 2009; Facebook, 2015) as well as that the nature of the use of the sites was in accordance with their terms and conditions. To increase accessibility, for example, I added 'alt-text' on each image – this is text that provides a brief description of the work and is picked up by screen reader technology for those with visual impairments.

Curatorial decisions

Choice of exhibit:

Of the 23 creators who proceeded with showing their work in *Exhibiting Pain*, 12 either sent me multiple works to choose between or directed me to their website. To begin with, while unsure of how many pieces I would feature in the exhibition, I informed creators that the number of works to be featured was unknown and that I might need to limit the number that I could include from each person. After a couple of weeks, I notified creators that I would be including only one work each but that, when data collection ceased, I would be happy to upload additional works, and/or links to their websites, if they wished. None of the participants expressed any displeasure with these arrangements.

I wished to limit the number of works in the exhibition to avoid it becoming overwhelming for a viewer and reducing the chances of all works being viewed. I was also unsure how the data collection would unfold and wished to avoid a situation with minimal data spread across a number of works which would prevent a depth of discussion on any one piece. Additionally, in consultation with my supervisors, I chose to restrict the exhibits to one per creator in order to avoid a bias being created by having one person's pain experience dominating the galleries.

Once the decision had been made to feature one work by each creator, I asked them to choose which piece they wished to include. It was important to me that the creator should decide which work was most important to them to feature. On one occasion the creator insisted I decide on a work from a selection on their website. As it was possible to view the statistics for the viewing numbers of each image, I calculated which work had received the most views, for the time on display (as they had been uploaded at different times), and chose that piece. In another instance, I narrowed down to three works and asked the creator to decide which one from that selection should be included. The importance of having the individual personally choose which

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work to exhibit was highlighted to me through discussions with my supervisors and the choice of one particular creator.

The creator concerned had submitted two works, one of which was particularly arresting because of the dramatic imagery and striking colours. Two of my supervisors were particularly drawn to the striking image while my own interest was piqued by the other work which was concerned with the invisibility of chronic pain. When I approached the creator, they chose the work I was struck by most (I had not provided details of my preference) stating that it was because of the lack of understanding concerning the invisibility of living with persistent pain (which was my own reason for preferring to feature this work). I feel that this decision by the creator demonstrates the importance of encouraging them to choose which piece to exhibit and shows the desire to voice their personal experiences of living with pain. It also illustrates that while it would be easy to focus on works with dramatic imagery and striking colour choices, the sensations of pain may not be the dominant message that the creator wishes to present to an audience.

Names:

Creators were invited to choose whether or not they wished their name to be included, use a pseudonym (of their choosing) or to feature as 'anonymous'. This follows Yu et al.'s (2011) finding that participants appreciate their autonomy being respected regarding the inclusion of their identity and is discussed at greater depth in Chapter Five, Ethical Considerations.

Titles and text labels:

Creators were invited to include the accompanying text and title for their piece of work, within ethical guidelines. I also added 'alt-text' for screen reading technology, as mentioned above. A large number of the creators who were recruited through Mark Collen and PAIN Exhibit stated that I should use the title and text accompanying their

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work on that site. Some creators sent images without title and/or text in which cases I enquired if they wished to add any additional details. Some responded not to do so, just gave a title, or noted to use that which is on the PAIN Exhibit site (if the works were featured there).

In one instance I intervened to add text where the creator had not provided any. This was in the case of an abstract artwork which I felt would benefit from some accompanying text to provide context for the audience. The decision to add interpretative text was based on a sense that accompanying information would aid viewers' engagement with the abstract piece. The text was taken from the creator's website which featured accompanying information for the series of abstract works (of which one was included in *Exhibiting Pain*). Having such additional information on their own website demonstrates an understanding of the need for interpretative text which provided an understanding of the works. I felt that the understanding of the work provided on the creators' website was engaging and interesting, as well as potentially helpful to connect a viewer to the abstract nature of the work. This decision was based upon my own struggles with interpreting abstract art and, perhaps unfairly, projecting these on to the audiences of the exhibition through my fear that they would struggle to respond to the work. I approached the creator to request that I use text from their website. The creator was amenable to this so I copied and pasted directly from the appropriate webpage. Other abstract works, in *Exhibiting Pain*, included titles or text which provided an element of context for the viewer and therefore may engage those who felt alienated by or uncomfortable with less figurative pieces.

In the case of another work, the creator got in touch with me sometime after the work had been added to the galleries, to request that the text be removed. The creator expressed concerns that they had not expressed themselves clearly and that the text was not helpful. In response, I sent an edited version (primarily broken up into smaller paragraphs with minimal editing of content) which the creator preferred and was happy to accept. I had wondered when posting the original text whether to break it up but felt that it was readable and that I wished to respect the creator's version. In some

regards, it read as a 'stream of consciousness', creating a powerful impression in itself. I shared anonymised responses to the work with the creator (which they would have seen if they had been a member of the Facebook group) to provide feedback and reassurance that the text was more effective than they feared. The creator was pleased to know that the work and its accompanying text had elicited understanding and support by viewers.

Choice of gallery platform:

The option to have work featured in one or other, or both galleries was provided. This was in order that those who felt nervous about displaying their work publicly may have felt a bit more comfortable with the greater privacy provided through the 'closed' nature of the Facebook group. Equally, some may have felt uncomfortable with having the work posted somewhere that they could not see (if they did not use Facebook, for example). All 23 creators opted to have their works shown on both platforms, perhaps reflecting the desire to have their experiences with pain recognised. Given that 70% of the creative pieces feature in the open format website of PAIN Exhibit this may not be surprising as these creators were clearly accustomed to sharing their works online and therefore less likely to be concerned about doing so. Four of the creators also have their own websites featuring works, in addition to being on the PAIN Exhibit site. However, this leaves 30% who were not already showing their work in PAIN Exhibit but were happy for it be publicly visible without the restrictions of the 'closed' group⁵. Given the online nature of recruitment it may be that this particular group were happy with the use of technology and sharing online. However, later some members of the Facebook group shared works with the group once they had built enough confidence to do so. Potentially this group would not have been willing to have their work shown on the WordPress site before getting a feel for what the project was about. These were participants who joined the Facebook group following the launch of the galleries, and their promotion, and were not already featured on PAIN Exhibit. Therefore, this may link to a bias in data created through the large proportion of creators sourced through Mark Collen.

Watermark:

Creators were provided with the opportunity to have a faint watermark added to the image of the work (a translucent white © symbol together with the creator's surname or pseudonym). This was to ensure creators could feel that the risks of their work being downloaded and reproduced were reduced. Where requested by creators, this was done by me, to the best of my technical ability, using the tools in Microsoft PowerPoint. Text was added, positioned and then faded to a translucent enough level that ensured it was visible enough to perform the role of protecting the image from being copied while not interfering in the viewing of the work. With some works this was quite time consuming and tricky, trying to find the right level, given colours used and position of focal point in the work. In one instance, one audience member commented that they found a particular copyright mark to be detracting from the work; consequently, I edited this and replaced the previous version in both exhibition galleries.

The gallery spaces

Images and screenshots of the online galleries are available in Appendix iii:
Screenshots of the galleries.

Facebook:

Using my personal Facebook profile (see Chapter Five: Ethical considerations, for more discussion on this), I created a 'closed group' on the site. To do so, Facebook settings required that I add another person, as it is not possible to create a 'group' with only one member, so I contacted a friend who has completed PhD research and understood the data protection implications entailed. My friend agreed to be added to the group in order for me to create it but did not receive admin⁹ status. Later, they became an

⁹ A Facebook group administrator has permissions not open to members and can control elements such as settings for posting to the page, who it is visible to, editing items, approving or blocking members.

audience participant also. If this friend had not wished to participate in the research, I would have removed them from the group once other members had joined (that is to say, once the membership numbers meant that I did not need this person to be part of it). I established the group under the group status/description of a 'project' and created a group description. Facebook requires that groups are set up with such descriptions, supplying options such as 'Project', 'Study Club', 'Support' or 'Hobby'. This was done at the start of my fieldwork year, while I was attempting to understand what I could do as an 'admin' in a Facebook group. Later, these postings and uploaded files (for example, information sheets and consent forms) were updated and could be modified as required.

To add artworks, I created a 'Photo Album' entitled 'Exhibiting Pain' and uploaded the images to this with accompanying titles, creators' names and text labels. This was visible to members once 'published'. I also published images from this on to the main group wall by 'sharing' them from the album which brought them to the members' attention. Sometimes I shared with a small comment, at other times I posted questions alongside (see below, Data collection). Later, it became apparent that it was not always clear to group members how to view the works besides scrolling down the page. I discovered that the page displayed in different ways depending on which type of device was being used to view it. For example, it varied on smartphone/tablet/computer as to where things were located in menus. The changing display format was an issue also encountered on the WordPress site.

I posted a piece of textile art in the Facebook group upon first opening it, to illustrate the sorts of things that people may share. This was done before the works had been uploaded, while I was still recruiting creators, as one member had shared details about craft activities that they do. While this was of interest, I wished to avoid it becoming a place that shared works unrelated to the representation of pain, at this early stage. Consequently, I posted a picture of a fabric artwork I had created as part of an earlier, personal, project with my Mum about my life with chronic pain. The work is shown in Figure 10, p. 154, and presents my pain management techniques.

WordPress:

WordPress provides free layout themes to choose between. The different layouts are promoted as being best for displaying, for example, photographs, travel diaries, projects, among others. After some trial and error, I found a theme which I thought would be effective, being promoted by WordPress as suitable for displaying photos as a gallery. However, once created I felt that it was not going to optimise browsing the works and lacked sufficient aesthetic appeal to draw in audiences. I applied a different layout option to the site and felt it was more suitable as it was easier to browse the works and more visually pleasing. The layout allowed me to create a menu from the titles of works on the left-hand side of the screen and featured a mosaic effect of images of the works on the right. These were randomised by the site and clicking on them would open a full screen version of the work and its accompanying text. This opened on top of the main page with a translucent black border and the images can¹⁰ be browsed left or right to progress to another image. By selecting a title from the left-hand menu, the audience member is taken to the work's individual page. At the bottom of each exhibit's page the site randomly created links to three of the other works, encouraging people to browse in different ways. This was helpful for data collection purposes as it reduced the likelihood of, for example, the first few works being viewed and not later exhibits as it was unknown if people would browse many works on the site or what method they would use to do so.

In the menu options on the site I added pages which reproduced the 'Exhibiting Pain Information' and 'Further Information for creators' documents, together with consent forms for each group (shown in Appendix vi). Additionally, I later added a page listing conferences where I was presenting the work (either via poster or oral presentation), with links to these as applicable. This was in response to one audience member asking in her feedback for more information about my method and analytical approach. While

¹⁰ The gallery is still live at the time of writing.

I did not include this information on the site (as I did not wish to detract from the works themselves and focus of the research), I realised that creators and audience members may like to know of the additional activities that were taking place throughout the research. In addition, I added an option for the 'Visitor Feedback Form' described below.

Data collection

Having detailed the process for constructing the two galleries on Facebook and WordPress, the format and techniques for collecting audience responses follows here. Among other things, the following demonstrates the development of the Facebook group into an asynchronous focus group discussion and the introduction of a Visitor Feedback Form (shown in Appendix vii) to encourage audience responses to the WordPress hosted exhibition.

Audience recruitment

Sampling of audience participants followed a similar strategy to the recruitment for works to be exhibited. However, this was broader in the hope of reaching those people who have no prior connection to persistent pain or arts for health organisations. For example, targeting relevant charity groups and organisations (through emails, website postings and social media contact), as well as encouraging word of mouth/snowballing recruitment. It was appropriate to use social media (including sites such as Twitter) to recruit participants, not only because it was the means by which the data was collected but because it has proved to be an effective method by which to do so (O'Connor et al., 2014).

By not recruiting a specific group of people to participate I broke with traditional sampling approaches to data collection. However, this was based on a museological approach to the research topic and attempting to retain focus on an 'exhibition', as far as possible. By doing so I hoped to consider the research question of how effectively

an exhibition of works may help to communicate the experience of chronic pain and the potential for using online exhibitions as a research method. I felt that recruiting a specific sample of participants may limit the value of the data gathered on this topic. However, if I had not received sufficient interest or participation, I had planned to recruit a specific group of participants (see Contingency Plan, below).

As it happened, audience members started to request permission to join the group as I began promoting it through various Facebook groups and pages (for example, those relating to pain, disability arts and others). In addition, flyers were distributed at events I attended or presented at, while an electronic version was used for the mail outs and for contacting other organisations by email. An element of 'branding' has been applied to the gallery sites, conference presentations, posters and flyers through the use of a logo style title and recognisable layouts (for example, the use of a 'frame' as a border for the posters). There was a surge in membership following a promotional email to various JISC ¹¹ lists, in particular in response to the British Sociological Association's Medical Sociology groups' email address. I believe that this was largely due to an interest in the novel research method I was using. Despite the growing use of social media to carry out research, there continues to exist a curiosity about researchers' experiences of using these platforms. Lunnay et al. (2015) note that their article was written in response to inquiries about their experiences of using social media to facilitate research interactions. Accordingly, there was a sense of my own research method, and by consequence me, being subject to voyeurism by researchers who were curious about method rather than the topic of the research *per se*.

When attempting to recruit medical professionals to give responses to the works I found that their responses pertained to letting their patients know about the project and encouraging them to participate. This was interesting in that it suggested they did not perceive a role for their own learning or feedback to works, focussed instead on

11 JISCMail is a site for email discussion lists for UK education and research communities, though it also has global subscribers (JISCMail, 2000-2019)

direct benefits to patients. Consequently, a more direct strategy to reach this audience may have helped to try and engage them in how it may be relevant to them as professionals.

As discussed in Chapter Two (the literature review) the use of online research methods had the potential to create a sampling bias as it may exclude those people who do not use the internet or may not have access to it (unless they were recruited through non-internet-based promotion and had support to access the exhibition(s)). Although the widespread availability of the internet (for example, in libraries, cafes and free Wi-Fi hotspots) and the proliferation of smartphones reduced the concern about audience access, they did not eliminate it. However, in keeping with Tates et al. (2009), a deeper and greater knowledge of the field can be achieved without aiming to produce generalisable findings. It was intended that the details gained from demographic information, collected through the surveys attached to consent forms, could be applied to the qualitative data, enabling groupings to be constructed which could establish more readily the transferability of the findings. Consequently, while the sample may have an inherent bias this will not automatically invalidate the findings or reduce their relevance.

Role of personal acquaintances

I carried out an informal trial of the method on my personal Facebook page to test whether an image about pain could generate discussion and responses for data. The pilot, though informal, was very successful and helped to increase my confidence in the method. Although I had some reservations about including my personal acquaintances in the audience group of the research (explored in Chapter Four, subsection 'The contribution of my personal acquaintances'), I approached a few acquaintances about participating and requested volunteers from my personal Facebook friends. I approached people who had expressed an interest in my work and/or had voluntarily participated in the pilot. My rationale was that the participation of these members in the formal *Exhibiting Pain* group would help to generate discussions. Through experience of moderating online tutorial forums as an Associate

Lecturer, I was aware that people can initially be reluctant to post comments in forums or online groups. Consequently, I felt that having participants who already knew me, to develop the discussion, might encourage others to take part (by inference those who knew me personally were less likely to be fearful about posting comments). I made it clear that continued (or any) participation was not expected or required. Some were, naturally, more active than others; however, a few individuals proved to be particularly valuable participants.

Demographic surveys and questionnaires

As possible interpretative differences based on demographic details was of interest in this research, surveys were included with the consent forms (these can be seen in Appendix vi). This included a questionnaire about the individual's age (banded options provided), gender ('prefer not to say' and 'prefer own term' options provided), nationality, profession and how they heard about the exhibitions/research. In order to ascertain if the exhibitions appealed to particular groups of people, audience members were also asked, among other things, whether they participated in any artistic activities, if they had visited a museum or gallery in the last year and whether they have persistent pain themselves, or some other connection to the condition (for example, through work or personal connections).

Creators were asked about the length of time that they've experienced pain (in order to examine if the type of works produced or decision to use creative techniques correlated to the duration of pain) and the origin of their choice to use creative methods to represent it. Additionally, creators were asked if they participated in creative activities prior to the onset of persistent pain and if they had a particular audience in mind for the work when they were creating it. I chose not to ask about the origin or nature of their physical persistent pain. This was in order to avoid a biomedical focus on the pain experience, to the neglect of the psychosocial elements of the condition. However, I provided an open question format for any information that they wished to provide on the nature of their pain experience.

WordPress

In WordPress, the blog software hosting the gallery, it was possible to allow audience members to post a comment on a work in the exhibition (and continues to be possible at the time of writing). This is a built-in function on the site which allows people to post comments in response to images or posts. It can be enabled or disabled as the administrator chooses. It was hoped that audience members would comment on individual works and/or the gallery as a whole to share their responses or interpretations, much as people leave comments in Visitor Books in physical galleries. Leaving a comment entailed creating a free account with WordPress (if the person did not already have one) which may have discouraged some people through the extra effort seen to be involved. While the Facebook group began to pick up respondents, the WordPress site was receiving visitors and interest but not generating responses or comments to the works. Consequently, following discussion with my supervisors, I decided to introduce a 'Visitor Feedback Form' [VFF] following approval from The Open University's Ethics Committee (shown in Appendix vii).

The VFF was included as a separate page on the WordPress site and added to audience consent forms and questionnaires as an option to complete; it was also posted into the Facebook group. Links were created at the bottom of each work on the WordPress site inviting people to share responses and thoughts. Although the links were created so that the page opened in a new tab this did not prevent audience members from finding that if they navigated away from the page to look back at a work (which I had hoped to avoid by creating it in the separate, new tab), the form's contents were deleted. I was unaware of this until informed by a participant who had been committed enough to complete it again. I added a message in bold at the top of the form to note that it was important not to navigate from the page for this reason. I do not know whether any other participants encountered this problem and chose not to complete the form again. Levels of participation are discussed below in Chapter Seven, sub-section 'Participation in *Exhibiting Pain*'.

Facebook

Individual works could be commented upon both in the Photo Album/Gallery section of the Facebook group and when shared onto the group 'wall'¹². This meant that people were able to give their responses to an individual piece without being directed by a particular question. Comments received were about, for example, the colours, overall effect, empathising with it or not feeling able to relate to it. Group members were also able to show a response to the work through Facebook's 'reaction' buttons:



Figure 3 Facebook Reaction Buttons

Data from the Facebook group was collected, in part, through asynchronous online discussions, in place of a face-to-face focus group discussion. To facilitate this, I would post a particular question in response to a comment made elsewhere, development of ideas following something I had been reading or previous note of a question of interest. In addition, I asked members if there was anything that they would like to ask the group (to which only one participant raised a question). Questions posed by me varied with how successfully they generated responses from audience members. I also experimented with using the 'poll' option in Facebook which entailed posting a question with possible answers that people could then select to 'vote'. There are also options to control whether respondents can add their own poll answers and whether they can choose only one response or multiple ones. On each occasion I left it open for people to choose as many as they considered relevant (in keeping with the questions asked) and for them to add their own options which others could also vote for. I

¹² The area on a Facebook group page or individual's profile where people can add their comments

posted three polls and they proved successful in engaging members of the audience who had not previously posted comments but were actively viewing the group. This proved to be a quick and effective way to generate audience feedback, as response rates were good, and the participants may have felt these were a less intimidating way to interact, rather than posting comments. The responses to the polls are discussed where applicable in the findings' chapters.

Group discussion was considered an appropriate way to collect data as it enables audience members to compare their interpretations, also to reflect on and potentially reassess these through interaction with other members. A deeper consideration of the interpretations could then be facilitated than is possible through, for example, open question or comment box formats of collecting interpretations, as used in the VFF. Creators were also offered the opportunity to contribute to the discussions, providing the potential to see the effect that discussing interpretations with the creator has on the meanings produced about the works by audience members (and fellow creators).

Discussion moderation

My experiences of using online forums as both a moderator and a participant (through my work and previous study with The Open University) ensured I felt confident that I would be able to facilitate the research effectively using this method to collect data. It is important to achieve a balance between responding to posts but not being overbearing by dominating the group. Drawing on Corkhill's (2012) experience that members of the therapeutic knitting online group, Stitchlinks (2005-2014), took some time to build enough confidence to participate, I felt the exhibitions needed to be 'live' for a little time to enable members' confidence to grow as they become acquainted with one another and the environment. Although I believe that an advantage to using Facebook was that those who chose to join the group had pre-existing accounts and were therefore familiar with the environment, this increased the likelihood that they felt accustomed to participating in conversations using the format (or at least familiar with reading them). My approach to the data collection time period also enabled people to answer questions at a later date if they then felt more comfortable doing so.

Breaking with previous research carried out via social media, I kept the data collection period live for a longer period of time than in previous studies (for example, seven days in Levine et al., 2011; and eight weeks in Kenny, 2005), with this occurring over six months. As mentioned above, this approach links to the natural audience growth I wished to create, mimicking visitors to a gallery. I did not remove or 'hide'¹³ earlier questions in the group which allowed for people to revisit questions (myself included) and for new members to respond to them as they joined the group. In turn, this led to renewed uptakes in activity, following notifications to participants of new postings, regenerating discussions and increasing the data.

Additional data types

In addition to the data generated through the approaches described above, some creators provided additional information about themselves, such as biographies. Additionally, there are statistics from WordPress and Facebook about visitors/members, viewing of works, levels of response to individual works and other details. The 'silent' members of the Facebook group constituted another audience. Mayne (2017) notes that in her Facebook research group, Woolly Wellbeing (concerned with women who share images of their yarn based crafts online), 26 percent of the participants were 'lurkers' (those participants who are members but are not interacting in the group). She notes that while they may not leave content to be analysed, their presence still forms part of the community and audience.

'Sufficient' data

Thompson et al. (2010: 2) note that the 'Facebook generation doesn't just wish to look, they want to *interact*' (italics in original). Who constitutes the 'Facebook generation' may be contested but this statement demonstrates that users of social media expect to be able to interact with material, express opinions and share their personal

¹³ 'Hiding' refers to removing the visibility of posts or comments, without deleting them

experiences. However, there is also the ability to be a passive onlooker in online environments, often called 'lurkers' these people login but rarely post comments (Sun, et al., 2014). It may be that these lurkers are akin to Corkhill's (2012) experience with participants needing time to build enough confidence to participate in online forums. Consequently, I felt it important to allow time for these groups to begin posting, to optimise the chances of them doing so. If closed too soon the data may have omitted an important audience type with common personality characteristics. As such, their interpretations may be different to those of the more confident 'dominant' contributors. To encourage those people who feel too shy to participate initially, and to allow sufficient time to recruit audience members, I proposed that the exhibitions would be 'live' for a period of at least three months. Additionally, I also offered alternative means to participate by stating that people were welcome to message or email me directly if they wished to share their thoughts but were reluctant to do so visibly in the group (no one took up this offer). Although it was expected that some members may choose never to participate which is why having enough time to achieve a large enough membership to ensure a level of activity was important.

Mayne (2017) notes that in Woolly Wellbeing, the number of significantly active participants are a minority, while participants engaged with different kinds of activities, such as asking for advice, answering queries or posting images of their works. Others were most likely to just 'like' a post, or comment, rather than create their own posts. Mayne does not provide statistics on this activity but the general sense of activity appears to accord with that in *Exhibiting Pain*. Details of activity in the Facebook group are discussed throughout the findings' chapters, where appropriate.

It has not proved possible to locate research following the method of asking audience members to respond to exhibition items through social media. Consequently, it was unknown how large a response may be generated. A reasonable 'common sense' estimation is that the data collection period would need to run for a period of between three to six months. However, following the initial three-month period, there were monthly reviews (with my supervisory team) of the data gathered in order to

determine how much longer the research gathering process would continue. If at four months there appeared to have been a low level of interest in the project by participants, I would have implemented the contingency plan, as detailed below.

The data collection period lasted for 25 weeks. It was brought to a close to be in keeping with the schedule developed at the end of my first year and because I felt that there had been a large enough quantity of data gathered. When the decision was made, I notified the Facebook group, and posted on the WordPress site, the date when collection would cease (this was five days' notice, ending at the close of the week, on a Sunday). However, I emphasised that the group and both sites would continue for the foreseeable future (to date, both galleries are still active). However, it was made clear to audience members that as this was the case, moderation of the discussions was going to be reduced. Accordingly, this has continued to be the case, however the group is less active and this has not posed any difficulties to date. In addition, discussions on the Facebook page after data collection ceased adds importance to the findings about the benefits of the group. It was therefore necessary to decide if it was possible to use this and how, without appearing to bias findings. A benefit to the continued existence and activity in the group is that it has been useful for me to 'verify' findings or ask questions related to things that have come to mind following the end of data collection. This has been aimed at developing ideas as opposed to the collection of additional data.

Data management

Managing the various forms of data proved challenging at times in order that it should be kept up to date and complete, as it was from various sources and in differing formats, as shown in 'Table 1 – Types of data' below.

Data	
Exhibits/works	Image/work content Accompanying text Accompanying title
Emails	Creators Audiences (Other/General response to the work)
WordPress	Comments on individual works Visitor Feedback Forms Comments/contact submitted to me via site Statistics – visitor numbers, country of origin, ‘clicked from’, viewing figures for works and number of views per visitors, external links followed
Facebook	Private messages Membership numbers Activity statistics (such as, interaction/responses to comments and works, active members) Discussion content Comments on individual works Timeline (for example, of interaction, responses to questions and works)
Creator Consent Forms	Demographic information Additional info about pain, interest in arts, use of creativity regarding pain
Audience consent forms	Demographic information Have Pain or not, additional information regarding interests in the arts, other connection to pain

Table 1 - Types of data

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Although not all data was used for analysis, it was maintained in order to keep a record of the research process. It was administratively demanding at times because of the need to follow up emails with creators about their exhibits and consent forms. I used a combination of Excel Spreadsheets and electronic filing systems; for example, folders in Outlook for emails from creators and a separate one for emails from audience members. An Excel spreadsheet was maintained with details of creators and their works; another was used for details of audience participants. I also used Excel spreadsheets to record visitor statistics from WordPress, Twitter data and Facebook membership. As I received images and text from creators, I set up folders on my computer for each creator. Within these I stored copies of emails and messages, image and word document files. Once they had chosen one particular work (where applicable) I created a PowerPoint file in which I inserted the image and created the copyright logo (where applicable). I also included the title, any text and pseudonym on the slide. This ensured that I had all details for each creator in one location, making it easier to upload to the sites.

Returning to the sites at a later time to gather additional information highlighted an issue not previously allowed for which was if someone had later chosen to edit or remove their comment, or had left the group. This meant that the data 'changed' depending on when it was collected or if revisited. It demonstrated to me that I would have benefited from a clearer plan at the outset for how I was going to record the data, for example, group members. As the group and data was constantly changing (for example, comments being added on old and new posts, members joining or leaving) a clearly defined data management plan would be advised in future research using such groups. As it was, I felt happy that I had sufficient details of group numbers and had also captured the data at a particular point in time and used that as the content for analysis. However, if changes to the group were to form part of a research study then it would be necessary to have a very clear agenda or timetable to the recording of this information.

The unusual nature of the Facebook group data meant that it was difficult to gauge the level of data obtained and whether it was sufficient to prove meaningful in addressing the research questions. However, as part of the decision to use this particular approach was to explore its potentials as a research data method, this concern was allayed in part through the quantity of data and its nature being part of the findings themselves. As such, it was therefore appropriate to take a somewhat pragmatic approach to the data analysis which is detailed next.

Data Analysis

Data analysis occurred throughout the data collection period, in order to assess the level of data being obtained and whether the contingency plan (see below) would be required. Analysis also continued during writing up, as themes became clearer and my thinking developed, in keeping with Barbour's description of analysing data as an iterative process which continues during the writing up phase (Barbour, 2014). All data types (as detailed in Table 1 above) were imported into the qualitative data analysis computer software package, NVivo 11 (QSR International, 2016). Data was sorted into folders according to type, for example Facebook posts, demographic information, Visitor Feedback Forms. A thematic analysis was carried out on the VFF content, details in consent form questionnaires and the Facebook posts. The creative works were themselves not analysed as they were not the object of study, rather they were being used as an elicitation tool (Mannay, 2016) to explore concepts relating to creative expression and communication of chronic pain through social-media hosted galleries.

On reading through the content, I created and assigned codes ('nodes') to sections of text as I was struck by particular elements. I assigned and created nodes for themes or points that I observed, without worrying about whether these crossed over with others, allowing me to immerse myself in the flow of the data. This meant that the nodes were sometimes very specific in content and I had a large number. I refined these by broad types, such as 'communication'; also, by merging nodes, such as those pertaining to mental health (ill health or positive). I followed this process through a

number of times, adding or refining nodes as applicable. Afterwards I examined which nodes had been applied most frequently in order to consider this data in greater depth. In addition, I reviewed the nodes that had been assigned five times or fewer. These were either merged into other nodes or deleted.

At this stage I wished to consider how the different nodes linked together across the types of data. I printed out the names of the nodes and cut these up so each was on a separate slip of paper. I was then able to view this at once on a large table and move them around into different groupings. For an additional perspective on the groupings I asked a fellow doctoral student to sort the slips into groups as they considered appropriate and then asked them to talk through these. During this conversation I was able to make links between nodes that I had not observed before and found this to be a valuable aspect of my data analysis process. Through this process I was able to group the nodes into three categories: The Creative Work itself, Phenomenology of Pain, and the Social Response (to the works and/or pain). Each category consists of three streams in total, each of which were made up of different but related nodes, these are illustrated in Figure 4 .

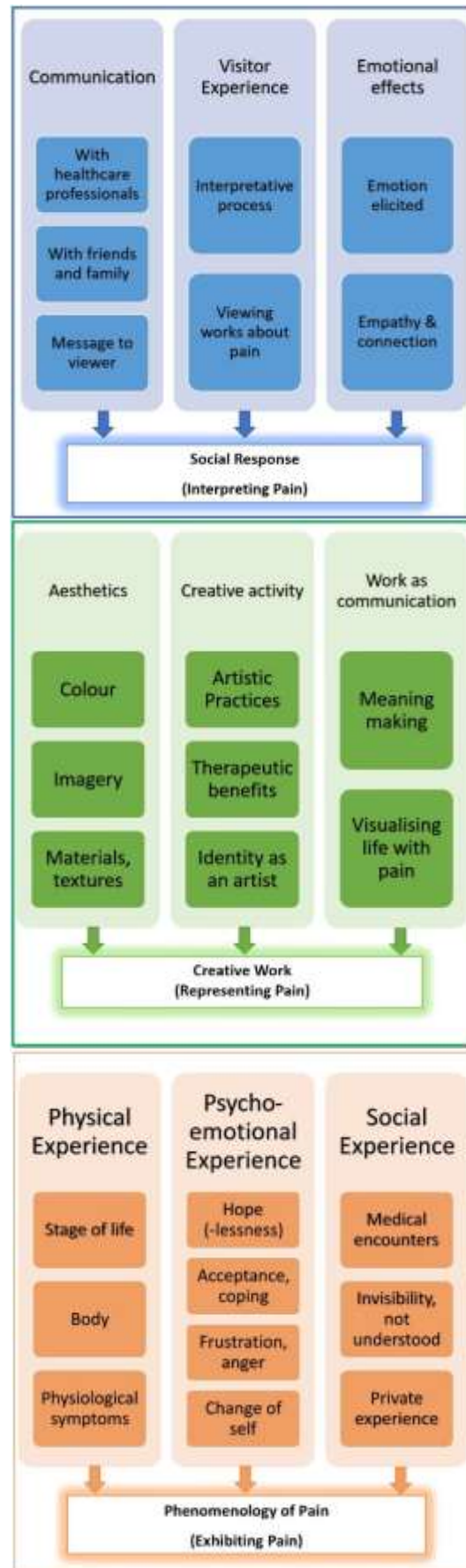


Figure 4 Data analysis themes

This was essentially a thematic analysis, seeking to discover the key themes which were identified in the data. These were influenced by my personal reactions; as Barbour (2014) writes, this is often the case as we are drawn to note, for example, the use of language which strikes us as interesting. However, a composite approach was involved in that elements of Interpretative Phenomenological Analysis were used, highlighting, for example, how participants in the Facebook group found it to be a supportive community in which they felt understood. Narrative analysis showed the differences in use of language used when talking about one's self with pain and others' pain. While semiotics was helpful in considering the use of colour and how it was interpreted in the creative works. Barbour (2014) observes that there is potentially much to be gained by drawing upon a range of analytical approaches, which are likely to be applied in an opportunistic way. Given that the data was 'bitty' and varied in nature it was appropriate to draw upon a composite of approaches in analysing it, to maximise the potential of what might be learnt.

Analysis and development of ideas continued during the process of writing up findings, which began by following the three broad categories shown in Figure 4, above. As Barbour (2014) notes, the writing up process can form another stage of analysis. This led to the identification of a conflict in the nature of living with the private and personal condition of chronic pain while seeking public recognition of the experience and empathy. In addition, this desire for empathy, and how it might be achieved by sharing creative representations of life with persistent physical pain, became significant. Consequently, I felt that these particular findings were significant enough to justify an adjustment from the original structure planned for the chapters presenting findings.

Descriptive statistics (for example, of the number of views each work received on the WordPress site) were obtained by carrying out statistical analysis in Excel, where I was able to produce visual charts; Excel was used as I already had the statistical data recorded in the program and am accustomed to producing charts using it. These statistics are of, for example, the number of creators broken down by gender,

nationality, age, among other things. Also, of the numbers of creators and audience members recruited through different sources (for example, via Mark Collen of PAIN Exhibit or through Twitter), connection to pain of audience members, age, nationality, and other factors. These are discussed as appropriate in the data chapters that follow and shown in Appendix i.

Contingency plan

At the time of designing the research method it was not possible to locate published studies following the same approach (and to date related publications are limited). Therefore, in developing the research design I drew upon studies using asynchronous discussions (as alternative means to focus groups) or semi-structured interviews online (for example, Yeo, 2014; Williams et al., 2012, and Levine et al., 2011). I was unable to anticipate the number of participants likely to be recruited for such a method; consequently, I proposed an alternative method, a 'Contingency Plan', in keeping with Barbour (2014), who notes that this can be advisable. This alternative approach would have been applied to collect responses to the works in the eventuality that there proved to be insufficient data generated to address the research questions. The decision to do so would have been made if assessed as necessary at a four-month review, following the launch of the data collection period.

In the case that an alternative (or additional) method of data collection was required, I proposed that at least three groups of participants (a mix of audience members and creators, where possible) were recruited, through purposive sampling, for specific asynchronous focus group discussions. Purposive sampling (Ritchie et al., 2003) was to be carried out by recruiting participants from those who had shown interest in the research. Research into the use of asynchronous discussions within education demonstrates that groups of between 3-5 participants appear to attain deeper levels of reflective or critical thinking (Thomas, 2013). However, Berry (2008) suggested a group size of five participants, with a variance of two, was the optimum number. While these studies are related to students' learning it seems reasonable to suggest that the

findings transfer appropriately to asynchronous discussions in the collection of data. Consequently, group sizes of approximately five participants would have been established. If it was felt that the original method had not generated enough data, this 'Contingency Plan' may have been implemented in addition, helping to develop ideas touched upon in the initial online discussions. However, sufficient creative works and audience interaction occurred and the contingency plan was felt to be redundant.

Conclusion

This chapter has detailed the development of the research questions, the epistemological approach of postmodernism to be applied to the research study, together with details of the design and application of the data collection methods. The management of data and its analysis have also been discussed, as well as describing the contingency plan for collecting data, had it had been required. Reflections on the method and recommendations for future applications of similar approaches to collecting data will be made in the final chapter, Chapter Eight: Critical reflections. Before proceeding to discuss the ethical considerations of this study, in Chapter Five, the next chapter explores my own experiences of living with chronic pain, the influence of this on the research study, together with issues surrounding vulnerabilities in carrying out research.

Chapter Four: The Pained Researcher: a reflexive consideration of the role of my pain in this research study

Introduction

In this chapter I explore the influence of living with chronic pain on my role as researcher during this project. This includes the process of accepting that it was something which needed to be given due space in the thesis, as opposed to passing acknowledgement. This is in keeping with the postmodernist epistemology applied in this study, recognising the socially situated nature of knowledge and corresponding need to know the researcher (Davies, 2008).

Ideas regarding the public-private dualistic nature of living with pain, and the need to perform both pain and health in differing circumstances, together with the desire to receive empathic understanding and validation, will be applied to my own experiences. This is done in order to establish transparency about the analytical process, recognising that my own experiences have influenced it. Establishing how these factors are relevant to my situation helps to add a further layer of contextual interpretation to the findings explored later.

The issue of the public-private dualism of pain is brought to the forefront in this chapter by examining my 'coming out' to participants and their responses to this information. The implications of this for the study is also considered. In addition, this chapter highlights some complexities to carrying out personal and sensitive research on the individual researcher, in particular a novice one. It also demonstrates some of the difficulties inherent to studying and writing about a pervasive condition, such as chronic physical pain, while also living with it. I begin by first considering the notion of 'insider' research and how it may enhance qualitative research.

Insider research and the use of reflexivity

The concept of insider-outsider status is used to highlight the degree to which a researcher is located within or outside a group being researched, through shared lived experience or status as a member of that group (Gair, 2012). Insider insight can be deemed as desirable and has been linked to the concept of empathy (ibid.). However, where experiences differed, even regarding the same issue, researchers have found it difficult to empathise, demonstrating that assumed similarities might not lead to the same view or shared experiences (Gair, 2012: 138) and that insider/outsider status is best seen as fluid or on a continuum as opposed to dichotomous. Zempi (2016) supports this view, writing of continuously negotiating multiple identities, and aspects of the research process, by moving fluidly within 'the space between' (Corbin-Dwyer and Buckle, 2009, cited in Zempi, 2016). This overview of the nature of insider-outsider research shows that it is possible to change position and use this to the advantage of the research, drawing upon shared experiences and understandings, or objectivities, as appropriate.

Milligan (2016) notes that much literature regarding insider-outsider researchers focuses on how the researchers view themselves in the process. However, it can be seen as a 'balancing act' between how the researcher actively positions themselves and how their role is defined by others (Milligan, 2016). It is important to bear in mind power relations and their impact on how the researcher may be perceived.

Participatory and creative methods are often used to 'give voice' to participants, in part to help address some of these power imbalances (Milligan, 2016). In the case of this research project, one reason I was eager for creators to choose which creative piece to exhibit, the accompanying text and their name, was to help redress any power imbalances between creators and me as the researcher. I believe that my later statement in the Facebook group about my own pain also helped to do this (discussed below). With hindsight, in order to address this power imbalance more strongly from the start, it might have been wise for me to declare my 'insider' status at the outset

but my concerns about taking away from the participants' experiences (mentioned below) led to me deciding against this.

Researcher subjectivity emerged as a point of discussion through feminist critiques of research approaches (Carabine, 2013). Such subjectivity has been considered problematic and as reducing the validity of research. I empathise with Richards' observation that her medical condition and self 'are so closely entwined that we probably cannot be separated' (Richards, 2008: 1725) and Barbour observes that 'we all use parts of ourselves in analysis' (2014: 276). As such, it seemed appropriate to me to follow Letherby's approach of a 'theorised subjectivity' (Letherby et al., 2013). Letherby acknowledges both the contribution and effects of researcher subjectivity, while allowing for a critical approach to how it is used and thought about. Arguing for an acceptance of research as subjective, power-laden and an emotional, embodied experience, Letherby suggests that this does not mean subjectivities should be indulged. Rather, Letherby argues that critical interrogation of both intellectual and physical personhood should take place within the knowledge production process (Letherby, et al., 2013). Following this approach, I occasionally include personal reflections in the chapters which follow, inserted within boxes and in a courier typescript. These are intended to highlight some personal reflections regarding the influence of my own experiences and pain on the development of ideas during the research process.

Davies (2008) notes of Panourgia's (1995, cited in Davies, 2008) research that membership of a family, when researching customs surrounding death, does not automatically mean that you have full access to all parties, as an outsider might, because pre-existing social relationships will influence this. Therefore, writes Davies, Panourgia observes that she cannot assume her insider knowledge to be 'either unquestionably complete or true' (Davies, 2008: 221). In my case, although I live with chronic pain, I do not use creativity as a means to express my experiences. I use cross-stitch to manage pain by achieving distraction and I participated in an art project with my Mum before beginning this study (to push myself to experiment with using creative

techniques to express my persistent pain experiences). Unlike the creator-participants in this project, creativity is not, for me personally, a natural form of expression or language. Consequently, I can draw on personal experience in understanding something of what it is like to live with chronic pain. However, when assessing the value of creativity to communicate the experience I am able to examine this with more objectivity than I might achieve were I myself an artist.

Richards (2008) writes that people living with illnesses are often seen as ‘objects of study and not as agents of study’, adding that ‘outsiders can only really be onlookers’ (2008: 1719), gleaning information about what the experience might be like but not truly knowing. Pain is a unique phenomenon in qualitative health research, argues Birk (2013), noting that scholars would benefit from attending to chronic pain as a public issue, which can best be elucidated by those living with it. Haynes (2006) argues, through her own experience of carrying out research, that reflexivity and emotion ‘are valuable sources of insight’ (2006: 217). Similarly, Ellingson (1998) asserts that drawing on her own experiences results in a rich, complex understanding. van Rysewyk (2016) states that the question of researchers reflecting on their personal pain experiences in studies has received little attention in published literature. However, he argues for investigators to do so as co-participants in their own studies. Consequently, there is a strong argument for utilising personal experience of a condition to facilitate research and increase understanding about chronic pain (within the limits of being able to understand another person’s pain).

In discussing autoethnography, Davies (2008) notes that it is through the process of interaction between ethnographer-as-self and ethnographer-as-other that social knowledge of interest and significance is produced. Richards (2008) writes that autoethnography differs from autobiography in that it is written for specific academic

purposes¹⁴. As such, the experiences are likely discussed and explored as data, as opposed to providing a narrative report. In the case of illness autoethnographies this can be a vulnerable experience but it is such experiences which bring many of us, in illness-related research, to our topics of study. As Richards describes it: 'My route to my present research...', by which she means her illness autoethnography (2008: 1718). Accordingly, I have attempted to provide an overview of my route to this research, which follows next.

A pained researcher: my 'credentials'

The need to set out my 'credentials' for being able to write about chronic pain is mentioned by Birk (2013), who states that it is fitting for her to do so because the establishment of credibility is at the centre of the experience of living with long-term pain. The need to write more than one paragraph, about my own experiences, is something which I have wrestled with and feels uncomfortable to me, both personally and in my academic role. The discomfort arises through fear of making the text too much about me and taking away from the wider community of those living with chronic pain, including the participants involved in *Exhibiting Pain*. Birk asserts that 'scholars of chronic pain need to make more room in the literature for the research of "insiders"' (2013: 397) and that the academic community would benefit from a greater number of first-hand accounts of persistent pain. Consequently, I have attempted to provide an overview of my medical experiences and the social impact that living with pain has on me (past and present). This is relevant to the discussions which follow concerning the public-private dualistic nature of pain and the need for an empathic validation of living with the condition.

I have experienced persistent physical pain for over 34 of my 39 years. There were episodes during which I did not experience pain, usually lasting less than a year, but the longest lasted two years, during my late teens. However, I do not recall life without

14 Brennan and Letherby (2017) suggest that when writing about themselves, while acknowledging the significance of others, academics' work could be labelled auto/biography.

pain or the knowledge, when pain had eased, that it would return. Richards (2008) notes that her illness is not the only thing defining her but that

there had been so little of me before it that I find it hard to
escape a medicalized view of my life (2008: 1721)

This is a sentiment I empathise with as my identity and personality have been shaped by a lifetime of living with pain and the corresponding experiences.

I was born with queried bilateral hip dysplasia and put into double nappies for three months. At this stage of review, I had to be put in a Von Rosen splint for six months. Such splints have been shown to lead to avascular necrosis¹⁵ in 1% of cases (International Hip Dysplasia Institute, 2018b). At review, a query was raised over one of my hips but I was discharged without follow-up. Aged 4.5 years I sat at the top of the stairs in my Mum's terraced house and said, 'Mummy, I can't come downstairs. I've got toothache in my hips'. X-rays followed and I was diagnosed with severe bilateral hip dysplasia and avascular necrosis of the femoral heads.



Figure 6 Splint for left hip,
nursed at home, aged approx. 6
years



Figure 5 Frog splint, aged approx. 5 years

¹⁵ Loss of blood circulation affecting development of bone in children and structural integrity (International Hip Dysplasia Institute, 2018a)

A series of procedures followed, including months in hospital in a frog splint from waist to ankle (Figure 5), following bilateral pelvic osteotomies (to alter the angle for the acetabulum/hip socket), with pins to hold the bones in place while healing took place. A femoral osteotomy (changing angle and shape of femoral head and holding it in place with plate and screws for healing) was needed the following year on the left hip and more plaster casts (Figure 6)¹⁶. On this occasion my Mum nursed me at home (drawing on skills developed through her nursing profession). Throughout all of this process I had some schooling in hospital and at home but it certainly was not akin to receiving a formal school education or socialisation with peers.

From this time (aged 5), until the age of 13, I had a number of stints in hospital for removal of metal work, bed rest and traction. I also went to school on crutches when necessary and able but also missed schooling due to pain. At 13, I underwent another femoral osteotomy, on the right hip on this occasion. I recall looking at my hip the night before and thinking it was the last time that I would see the side of the thigh without a scar, but at least my scars would now be symmetrical. The metalwork also had to be removed at some stage afterwards (due to still being at an age where I was growing) but I do not recall this except for being adamant with the surgeon that 'I must have the metalwork afterwards'.

Aged approximately 15-17 I had two pain-free and mobile years. At this time my school attendance suddenly changed from having missed an entire term aged 13, and frequent weeks off school, to missing only one or two days during the year. Having always believed I was not as intelligent as my peers, I began to see that I did have academic abilities when I was able to attend school more regularly. There were some

¹⁶ When hip dysplasia occurs, it is most commonly in the left hip due to the position during pregnancy (60% of hip dysplasia's in the USA are in the left hip only, 20% in the right hip and 20% bilaterally) so it is not uncommon for the left hip to be more severely affected when occurring bilaterally (Storer & Skaggs, 2006).

subjects where it was easier to compensate for absences than it was for others. For example, languages and sciences were difficult as the foundational knowledge was often incomplete and unconsolidated for me. Humanities were much easier to be able to adapt to following periods of absences.

There was another significant impact on my school experiences, which relates to the social difficulties of living with chronic pain and not being believed. Aged 14, my friends decided that I was lying about the pain, or at the very least exaggerating, in order to gain attention. This triggered a broader bullying strategy against me but was initially focussed upon me not 'looking' like I was in pain. Over a decade later I experienced discrimination and bullying in the workplace because it was decided that my pain was *too* visible, making people feel uncomfortable. The conflict this left me in was significant as it felt like a 'no-win' situation. I had been unaware that my pain was especially visible but also could not help but be conscious of the irony following past experiences and the fact that people claim pain is invisible. My sister has always disagreed with this latter point, stating that my pain is very visible if you know me well enough. This raises an interesting point about who recognises it, how and why, as well as how effectively we are able to hide it and when.

When I was aged 17/18 my pain began to return, though it started in my spine. It took another 20 years to receive an explanation for my spinal pain (Scheuermann's disease which entails the wedging of vertebrae as they grow during childhood and puberty, possibly linked to avascular necrosis, and some other related conditions). Day-to-day, back pain is what causes me the most discomfort; however, people always ask about my hips because this is the known factor, they are shocked when I say my back is the bigger problem. The response to this is usually to change the subject. There is only so much pain someone can bear to hear about.

My hip pain returned not long after and by the time I had completed my A levels it was of growing concern to me. As stated above, even during the times of being pain free I

had always known it would return. After-all, when I was a child, my consultant had predicted that I would be needing hip replacements in my early 20s. I recall that when I was 18, I walked a distance I could previously manage without consideration, but arrived at my destination in tears. It was not the pain itself but the implications which led me to cry. I was referred to a specialist orthopaedic hospital and further surgery was carried out on each hip when I was 19 and 20, with a follow-up corrective operation a year later when bone growth had not occurred (on that occasion I was discharged from hospital on my 21st birthday). Bespoke ceramic total hip replacements were built and implanted when I was aged 22 and 23. (After years of responding 'a new hip' to enquiries about gifts for birthdays and Christmas, I was fortunate to receive one from the NHS on my 23rd birthday!) The decision to use ceramic-on-ceramic replacements was because of my age, as they wear at a slower rate than the metal equivalents. However, research is currently mixed regarding their success, suggesting that they fail at the same rate but for different reasons and evidence is still limited due to the short amount of time such technology has been used. Neither hip replacement has led to an absence of pain but they did allow me to retain mobility and independence for longer than I might otherwise. In itself this point demonstrates one of the many complications with explaining the nature of chronic pain, as associated levels of function and mobility may not correlate with the pain levels themselves but with the mechanical function instead.

In 2018 I underwent further surgery to have a revision total hip replacement on my left hip. Of both hips it was the one which had caused me the most difficulties and did not feel stable. It had been 15 years since I had last undergone open surgery and, for various technical reasons, this was a complex revision. Since beginning my doctoral studies, I have experienced unprecedented triggers relating to hospitalisations which are distressing. Consequently, the impact of this operation upon me was significant, both physically and emotionally. Undergoing the surgery at the point when I had begun writing my thesis was not insignificant to the experience of both being in hospital and the writing up when I returned to it. The reminders of the lived experience of hospitalisation increased both my objective and subjective reflexivity on

the data from *Exhibiting Pain*. Such experiences confirmed for me that someone is never truly an insider or outsider researcher when it comes to researching something where our personal experience is involved.

For example, on the night of my operation I experienced tachycardia and hypotension, setting off various alarms and bells, leading the on-call doctor to be bleeped. He asked about my pain levels and suggested I take some opioid-based pain relief. I had been clear that I wished to avoid this as far as possible because of a physical dependency upon it, formed by about 15 years' use at high levels (this means that even very small quantities of opioids create significant withdrawal effects for me, despite having ceased regular use of it over 10 years ago). I said, 'It's OK, I have chronic pain anyway, I can cope.' He remarked that post-op pain was a little different and, chronic pain or not, there was no reason to suffer (despite my having explained my reasons). I said, 'I don't suffer pain, I live with it.' I had to laugh at myself for being an obnoxious know-it-all patient, even when I was less than 12 hours post-op. However, he paused for a moment, looked at me, squeezed my arm, nodded and went on his way. No doubt he was cursing the obnoxious patient but I hope it was also a thought-provoking moment for him.

I had attended a three-week in-patient pain management programme after ceasing to use opioids, recognising that I was struggling to manage to work and had poor quality of life. Such multi-disciplinary programmes are often seen by patients as a last resort after trying everything else. Being led by psychologists means that there is often a fear that those referred to them are being told the pain is in their heads. I had been referred to a psychologist or psychiatrist (I do not know which) when I was a child, by my orthopaedic consultant. This was after he had been unable to find a cause for my continued pain and I was certainly left feeling that I was being accused of it being in my head or inventing it. I am fortunate to come from a medical family with parents and step-parents all in the profession. I believe that this influenced the way in which I was able to engage with treatments and the scientific basis underlying certain practices, such as pain management programmes.

When I was 13, thanks to my step-dad having a professional interest in pain management, I was able to become an active participant in the management of my pain – engaging in conversations about trying different medications. Later, aged 19, I chose to read Patrick Wall’s seminal book *The Science of Suffering* (1999) and learnt about different understandings and treatments of pain. When I was 22 my mum sent me a copy of Daudet’s *In the Land of Pain* (2002). These moments have stayed with me because I believe they have helped to shape the way in which I understand my own pain and how I have come to engage with the field as an active patient, rather than passive. Indeed, people have remarked on my use of ‘we’ when referring to the medical decision-making about my care since aged 18. Accordingly, most commonly I refer to my surgeons by their names in conversation with family and friends. People are surprised by this use of language as patients generally say ‘*they* want to...’ when talking about treatment decisions. Often, when relating illness narratives, reference is made to ‘the doctors’ (as Birk, 2013, does), or ‘the rheumatologist’, without names and homogenised into one body, much as patients are identified by their condition and bed number on a hospital ward (‘the revision hip in bed 7’) rather than by name.

I believe that it is important to recognise my own role in making these decisions, such as proceeding with hip replacements at the relatively young age of 22. There are implications for longer-term revisions and care so this was by no means a small decision, just as the revision at 38 also has significance for longer-term needs¹⁷. Consequently, my surgeons have always emphasised such implications with me and ensured that I was aware, and informed of, the evidence base for longevity of replacements, different materials and such like. As an orthopaedic patient I also have a role to play in my treatment and recovery (for example, physiotherapy exercises), just as the surgeon does in carrying out the operation. Therefore, it is appropriate to me that I take responsibility for my own decision to proceed, for better or worse.

¹⁷ More details about this can be found in Main (New hips for old, 2018b).

Over the course of my one week stay in hospital in 2018 I had to explain my reasons for refusing opioid relief a dozen times. Medical professionals were stunned and continued to suggest I took some, despite the same people also remarking that I have high pain thresholds. I began to consider the role that medics play in fuelling the understandings that we have about managing and living with pain. If a patient is eloquently able to advocate their own needs and right to refuse opioids, should medics continue to promote such medications to them? While it is the role of the medical profession to 'cure' certain ailments, there is perhaps the need for a greater understanding of how to treat patients for whom chronic and acute pain are intersecting.

I have a selective memory of most of these experiences, as something of a self-protection mechanism, and I am grateful for it. There are some memories I do have which are very distressing, including my first night in hospital when I was four years old. However, I also recall waking up to the sight of the pins (from the pelvic osteotomies) in an empty specimen pot on the bedside table. Since then, I've been very clear about wishing to keep metalwork following its removal – it forms something of a collection now (see Figure 7 below). I was disappointed that I was not permitted to keep my old hip replacement when it was removed last year!

While I write this somewhat jokingly, it is symbolic of the role that such material culture can have in the experience of surgery and living with a chronic condition. In the case of an invisible condition, such as persistent pain, these items take on an added role in that they provide a referential object which can be seen, touched and shared with others. The use of walking aids helps not only with mobility but to provide 'proof' to others that there is something wrong, as well as reassurance to myself, acting as something of a security blanket. As Birk writes, when not appearing to need a disabled parking space, 'I learned that day that I needed "props" if my pain was to be taken seriously' (2013: 394). Ironically, walking aids have caused their own problems for me

in the wear of joints and damage to nerves, muscles and tendons, making the decision of whether or not to use them sometimes difficult.



Figure 7 Metalwork collection

The metalwork collection helped to address some of the doubt I was subjected to at school. When ‘show and tell’ took place, I did not need to think too hard about what to use. However, the other side to this was the experience that if I had received surgical interventions (as proven by such metal hardware) then I must be better now. This became greater when I underwent total hip replacements. The issue of injuries being healed, or conditions operated on, and pain persisting flouts the social norms of medical care and recovery. I’ve experienced this not only in social interactions with people known to me but also strangers (comments such as, ‘you’ve had hip replacements – at your age?’ and, ‘You’re still using crutches – it must have been recent then’). In addition, I have had to appeal every review of my disability benefit because of misunderstandings relating to the invisibility and variability of the condition – in particular following the total hip replacements when the expectation was that I was now ‘cured’, at least for the next 20 years.

It is interesting to me that, having struggled considerably to start writing my own pain narrative, after some time (and wine!) it took over as a story that wanted to be told. Perhaps this was my fear in starting it, relating to the fear that I would begin to dominate the text, because there is such an inherent need to relate the story that sometimes it needs to be reined in. Additionally, where the narrative links to an invisible and misunderstood condition, such as chronic pain, the need to attempt to explain is all the greater.

I believe that the narrative above is representative of my very need to receive recognition for the private and personal experience I live with. Confounded for me through occasions of having been stigmatised for my pain not being visible and for it being too visible. These experiences have resulted in me living with the conflict of needing to publicly acknowledge my pain for my own sake and mental health, and wishing for others to recognise it. However, I am conscious of the need to balance this with the awareness that any pain is generally too much pain for others to bear witness to, leading to the internalisation of it.

de Montalk (2019) describes wrestling with finding a 'tonal balance' between memoir and aetiology when writing about her own pain and this is something I have also experienced. Relating my narrative above, I am aware that I have not fully explored a number of aspects of my pain experience. Instead, I have 'defaulted' to a primarily medical history style narrative because this is what I am used to providing. As Richards writes, illness narratives become stories of disease rather than stories of the impact of the illness on a person's life (Sullivan 1986 cited in Richards, 2008). I also believe it is more palatable and communicable than providing detailed descriptions of the various physical pains and sensations at different times. As de Montalk writes, 'I was reluctant

to engulf readers with pain, knowing there would be few compensating moments of lightness and humour' (de Montalk, 2019: 189). I doubt very much that I could describe the various pain sensations; as pain is something which exists so much in the present moment, it is somewhat elusive in memory. While my own pain never entirely abates, it changes. It is almost like the UK's changing weather with the phases it will go through and its unpredictable nature. However, there is always some pain somewhere in my body at any one time. Often, I joke it would be simpler to list the parts of me that do not hurt.

This is a coping mechanism because I still have not learnt how to respond when people ask me about it. I find myself providing an element of consolation or comfort to them when they are clearly embarrassed or regretting their query. I will state something along the lines of, 'don't worry, it's permanent,' as though permanency is less of a concern than a passing incident! My meaning is really, 'I'm used to it'. It is difficult to give any response which is suitable, and keeps the tone light enough to allow the conversation to move on, without making some sort of joke which belittles my pain and experience. In doing so I am confounding the issue of chronic pain not being publicly recognised as the consuming and sometimes debilitating condition that it is. These experiences are related here because they are demonstrative of some of the difficulties in knowing *how* to talk about one's own pain, when talking about it is indeed possible.

The contribution of my personal acquaintances

Recruitment of my personal acquaintances to the audience participants in the research is discussed elsewhere, in the Method and Ethics chapters (Chapters Three and Five respectively). The contribution of this group had the potential to provoke discussions between us which we had not previously held. While I had ethical concerns about the inclusion of personal acquaintances as participants, on reflection I considered that there could be an argument in favour of it. While those living with chronic pain may often feel silenced and overlooked, their support networks are likely to do so also.

Persistent pain impacts on all areas of an individual's life, including interactions with other people, creating irritability and impatience (Sheppard, 2017) and affecting relationships (Flor et al., 1988; Main, 2014). de Montalk (2019) discussed the impact of her pain with her husband, reflecting on things they were no longer able to do as a couple, possible frustrations and what it is like to live with someone with pain. de Montalk's husband observed that any frustration passed and he had adapted, enjoying not socialising too much and, while the pain may be a 'dampener', he understood she was not 'putting it on' (2019: 80-81). However, personal experience means that I am aware that not all relationships remain so strong through the onset of pain and change to life. The emphasis may become focussed upon supporting the person with pain, while the impact on others may be overlooked or deemed inappropriate to consider. I encountered such a couple at the pain management programme I attended. During the question and answer slot at the pre-programme assessment, the partner without pain asked if there was any support for family members. The psychologist looked rather taken aback but I think it demonstrates that there is a gap in providing assistance to the support network of the person living with pain. Denying a voice to this group of people, and the chance to express their thoughts about pain, is placing a limit on the support that may be given to the person with pain also.

Declaring my subjectivity

Given concerns relating to being believed, by those living with chronic pain, I wondered whether it may be necessary or helpful for me to declare my personal interest in the subject with participants. Richards (2008) describes telling her urologist of her intention to pursue a doctoral qualitative study relating to chronic kidney failure and transplantation:

'What qualifies you to do that?' he asks.

'I lived it,' [she replied] (Richards, 2008: 1717)

As Richards shows, lived experience as knowledge may be commonly overlooked by professionals but for those living with chronic pain it can be helpful in knowing that

they will be believed and understood (as far as is possible to understand another's experience with pain). Sheppard (2017) spoke of being open about living with pain with her research participants, stating it felt deceitful not to be and recognised that it would help to overcome the sense of not being believed, as well as providing an opening to discussion. As I became increasingly aware that my subjectivity was going to need to be included as part of the thesis in its own right, I was interested to know what response the participants would have to knowing that I also live with pain. The post shown in Figure 8 was made to the Facebook group three months after it had been established.

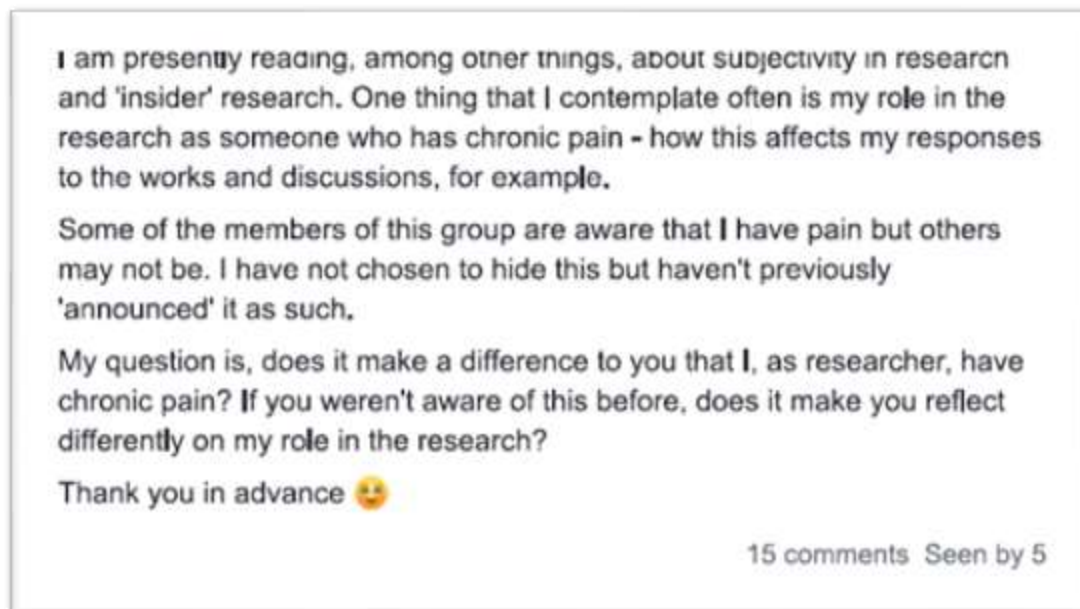


Figure 8 Declaring my own chronic pain in the Facebook group

August (Pain Unknown [PU]) was the first to respond and stated that my having pain meant that I was more 'sensible to and aware of some issues,' adding later that

no pain experience is alike another. So you have to make an effort, just like any other researcher, to understand the experience of another person living with chronic pain

Dylan (Creator [C]) wrote that they had been surprised to find out I have chronic pain, stating that they felt

it gave an added dimension, as well as, for me, an explanation as to why you have chosen cp for your area of study

Jude (P [Participant with pain]) posted the following thoughtful response which I provide at length to demonstrate the multifaceted nature of the topic being discussed and the consideration provided in the reply:

I think it would be interesting in itself to hear reflections from researchers both with and without chronic pain [CP]. I think unless you've experienced CP you perhaps aren't aware of the immensity and complexity of it. As with everything though, reflectivity is key as it would be easy for a researcher with CP to have a strong bias – in fact it may be easier for a researcher without CP to retain others' voices in the research? I'd be interested to hear how you find the process? (Jude, P)

This comment raised points which I had been mindful of and mentioned above, such as the potential bias and if it would be difficult to retain the voices of the participants in the research. Reflexivity is described as being about 'ways of seeing which act back on and reflect existing ways of seeing' (Clegg & Hardy, 1996: 4, cited in Alvesson & Skoldberg, 2018: 329). I think that having an awareness (from the outset) of the concerns raised above has helped me to give them due consideration throughout the data collection process, analysis and write up. For example, when discussing some findings with my supervisors I noted the theme of empathy and talked about this. One supervisor noted that it sounded as though I was talking about recognition also. My response was that I had been thinking about the topic of validation and recognition in relation to the findings but was uncertain if this was a projection of my own experiences on to the data. In having this reflexive approach to the data and my interpretations of it, I was able to engage in an iterative process, returning to the data as needed to support my findings and using supervision as a means to triangulate my analyses. Consequently, my consciousness of the possibility of biasing the findings allowed me to be cautious and careful in assigning codes.

There were two incidents of note during the process of setting up the galleries and over the data collection period. The first was when one creator had not heard back from me, after a couple of days, in response to their email about submitting a work. The person contacted Mark Collen, through whom they had heard about the project, and complained to him. Mark responded, saying to give me more time and mentioned in passing that I also live with pain. The follow-up response I received from the creator was prolifically apologetic for their own impatience and acknowledging my experiences with the condition. It was interesting to me that this piece of information had made a significant difference to the creator concerned (who has gone on to be very supportive and enthusiastic about the project as a whole), who clearly felt that different standards or expectations should be applied to me as someone with chronic pain and fatigue.

In another instance, I had corresponded with a creator about something to do with their exhibit¹⁸. As I had replied quickly and proactively, the response I received included a comment that I reminded them of themselves before they had pain. I then felt it would be inappropriate to mention (at least at this juncture) that I also live with pain. This highlights some difficulties of disclosure to those with and without pain. This is picked up on in the findings in Chapter Seven, sub-section 'Clinical encounters', when discussing medical professionals' personal experiences of pain. It is also illustrative of assumptions that may be made about others' experiences of illness.

The vulnerable researcher

Vulnerability in research is discussed by Ballamingie and Johnson (2011) regarding professional implications for researchers, for example where consent is refused for publications. The authors note that existing literature regarding researcher vulnerability is scarce and relates to the emotional impact of carrying out (primarily) health-related studies. My own experience with vulnerability during the research

¹⁸ I am intentionally keeping this somewhat vague to reduce likelihood of identification

process was multi-faceted but did include elements relating to me on a professional level. Using an unusual method of data collection led to a particular interest in *Exhibiting Pain* from the academic community. Evidence for this interest is discussed in Chapter Seven, sub-section 'Viewing'. As a novice researcher who was uncertain that the method would successfully enable me to gather data, let alone answer the research questions, I felt very self-conscious about it. Using online methods, the data collection process has been largely visible, leading me to feel subject to a certain amount of voyeurism of it and somewhat vulnerable professionally. This was augmented through the presence of my personal acquaintances in the Facebook group which meant that if the research proved difficult, those I know personally would be witness to it.

There is a sense of responsibility (as well as an ethics of care, see 'Chapter Five: Ethical considerations') to hear the stories of illness and provide personal acknowledgement to individuals revealing their pain and experiences. This has an emotional impact upon the researcher. As Jamison (2014) wrote, of confessional writing and *The Empathy Exams*, when strangers contacted her, she felt they were asking for empathy and that she owed it to them, which can create an emotional burden. Having a publicly promoted research project, which proactively encouraged people to connect with the works and respond to them (and therefore me), led to contact from those with pain who wished to express their empathy and gratitude (this continues to be the case at time of writing as the websites are still active, as discussed in 'Chapter Eight: Critical reflections'). As Jamison (2014) experienced, presenting yourself as someone who understands, elicits confidences and the relating of personal experiences. Having encouraged this to some degree, by carrying out research about the experience of living with chronic pain, I have felt a sense of obligation to respond to and acknowledge such contact when receiving it. For example, I have received emails from people stating how powerful and helpful they've found the creative works because they encounter a lack of understanding of their own experiences. The reverse to this is that such contact has provided evidence that the project had impact and meaning for a range of people which has helped to keep me motivated.

Encountering a participant who was threatening and abusive via email (and an answer-phone message) was an emotionally difficult experience (further details are provided in Chapter Five, sub-section, 'Encountering a difficult participant') which resulted in me fearing the making of further decisions or actions. This led to some delay in getting discussions active in the Facebook group through trepidation about what responses may be received. My own response to this situation surprised me somewhat as I had previously worked in a role where I was the first-responder to people making complaints to our organisation and when there were possible safeguarding concerns. Consequently, I had experience of responding to complaints and difficult situations calmly and effectively. However, I was influenced by personal events which had occurred between experience in that job role and the research I was now carrying out. As such, the tone and language used by the participant acted as particular triggers for me to pre-existing post-traumatic stress. On reflection, this situation could not have been foreseen though there were certainly actions I could and should have done differently which may helped to avoid it (also discussed in the appropriate section of Chapter Five). While the situation could not have been anticipated it did highlight that where a researcher is sensitive or vulnerable in some way particular consideration may need to be given to their coping mechanisms and support system. Additionally, while there is a great emphasis upon protecting participants in the research process there is little consideration given to the experience for researchers of responding to difficult situations or people.

Discussing this situation with my peers I discovered that others had experienced difficult situations for which they felt unprepared also. For example, the revealing of a safeguarding concern during an interview and a participant calling a doctoral researcher at night in distress (relating to the topic they had discussed during interview). The latter also highlighted that some researchers use their personal mobile phones to contact participants, putting themselves at risk of harassment. While there are methods in place to avoid or support students in these situations it suggests that there may need to be greater safeguarding awareness training provided before

students enter the field. It may also be appropriate for supervisors to check what approaches students are taking to contacting participants and perhaps carry out 'de-brief' telephone calls to check on safety.

This is a point supported by Bloor et al. (2007) who report on physical and emotional risks and institutional risk management in relation to qualitative research. This includes being aware of possible physical risks during research settings, such as home interviews, but Bloor et al. also advise consideration of the context of funders, institutional bodies, ethics committees, supervisors and others when assessing such risks. The authors note that emotional risks are discussed in the literature through a focus upon protecting participants but this has neglected researchers protecting themselves (2007). Good fieldwork relationships are described as requiring emotional labour which is draining, while empathy may generate distress. Institutional support is noted as being more limited and safety training for researchers inadequate. However, the formal structures available in universities are reported as under-used and therefore may provide sufficient support systems if put in to practice more effectively. In my case I felt that I was provided with sufficient and effective support from the university and discuss this in Chapter Five, where applicable.

Pain begets pain... the pain of writing about pain

One of the most effective ways to manage life with chronic pain is through distraction techniques (Butler & Moseley, 2012). However, the act of studying and researching pain makes this inherently difficult, as well as the pain itself impacting upon thinking and writing processes through its distracting nature. Birk (2013) writes,

shots of pain here and searing aches there cannot help but to
distract the writer's train of thought and so to punctuate the text
in question (2013: 396)

de Montalk states that she underestimated the 'challenge of sustained thinking and writing about pain while living within it' (2019: 188). Her description of this experience

is worth giving at length because it demonstrates that thinking and writing about pain, while living with it, is a complex process:

I struggled to bestow detachment and balance upon the intense reality of a body in pain. Whereas writing creatively offered a degree of imaginative distraction, arguing for or against the behaviours and meanings of pain within the rigour of scholarship only served to engage and re-engage the overloaded parts of the brain marked 'pain'. The subject, actual and academic, became a double bombardment (de Montalk, 2019: 188-189).

de Montalk's doctoral work used creative writing to communicate what it is like to live with persistent pain, drawing on her own experience. While she engaged with works written by others about their pain, she did not enter into discourse with participants for the work. However, Sheppard (2017) noted the emotional toll that talking and thinking about pain with others who live with it can have in the doctoral process. Sheppard describes her experience, noting that while transcribing, listening to and reading her participants' discussions about their pain, she had been unaware of her own due to its persistent nature being normal to her. Sheppard states that the experience created a bond and shared understanding with her participants. Through the sharing of pain experiences and engaging with participants' stories of pain, she describes experiencing their pain as 'shadows' (2017).

My own experience has been difficult because the very act of typing the word 'pain' causes my body pain! Fatigue and pain related aphasia¹⁹ mean that dictation has not been effective for me as it entailed a different kind of 'flow' in thinking from typing/writing. Simultaneously, the irony of reading about the impact of pain upon fatigue and concentration levels was not lost on me. In the process of the doctoral research as a whole I have been led to reflect on my own experiences of living with pain, by engaging with the literature in the field and discussions at conferences, with participants and others. As such there has been little escape from thinking about pain,

19 Most people with aphasia experience difficulty expressing themselves or understanding things they hear or read (National Health Service, n.d.)

increasing awareness of my own pain levels at times. While this has increased my empathy for participants it is not without its own emotional burden.

Conclusion

This chapter has explored the role of living with chronic pain on myself in order to achieve a level of transparency and reflexivity regarding the influence of my experiences upon the research discussed here. I have discussed the sharing of my pain status with participants in the *Exhibiting Pain* Facebook group, together with their responses to the information. In addition, vulnerabilities of carrying out research, in particular as a novice, and the influence of doing so about chronic pain, while living with the condition, have been highlighted. The following chapter will explore ethical considerations entailed in both the method used to collect data, the topic of research and the experience responding to a difficult participant.

Chapter Five: Ethical considerations

Introduction

This chapter provides a discussion of the ethical considerations encompassed in this research project. Included, among other topics, are issues relating to the consent of creators and audience members, exhibition of potentially distressing content, copyright and possibly upsetting or offensive comments. Additionally, experiences with an unhappy creator-participant are discussed, highlighting the potential for encounters with aggressive and verbally abusive participants, as well as the implications of this. The complexities of managing online research and using a Facebook group to carry out research are outlined and the implications for ethical guidelines and decisions are discussed.

Given that research is contextual, the dilemmas arising are specific to that situation. As such, it can be argued that ethical dilemmas need to be responded to individually as they arise, within the context in which the research is conducted (Wiles, et al., 2008). This is appropriate given that ethics are socially constructed and contextual (Gazi, 2014). Many ethical challenges in carrying out arts-based health research remain unaddressed and the guidelines that do exist are not explicit enough to provide solid guidance (Cox & Boydell, 2016). Issues include ownership of the items produced during the research (especially when artistic collaboration has been involved), possible identification of participants, and methodological issues, such as how to analyse artistically generated data (Cox & Boydell, 2016). While not all of these issues were applicable in *Exhibiting Pain*, noting them is helpful in order to highlight those areas where ethical guidance in arts-based research is presently limited. With an unusual method of collecting data and no published precedents to draw upon for guidance at the time of fieldwork, ethical decisions were made pragmatically in accordance with Wiles et al.'s (2008) approach of responding to them individually, in context, as they arose.

One approach to ethical decision-making in research is that of an 'ethics of care' (Wiles, et al., 2008). Through this approach, decisions are based on:

care, compassion and a desire to act in ways that benefit the individual or group who are the focus of research (Wiles, et al., 2008: 7).

This tactic is used often in feminist participatory research where close relationships develop between the researcher and participants, and it was the approach taken to ethical decisions arising in this research. For example, when considering the appropriateness of people using their own names, how interpretations were gathered and the assessment of whether or not to close the online gallery sites following cessation of data collection.

Ethical approval

Approval from The Open University's Human Research Ethics committee was applied for and obtained, following submission of the HREC-Proforma. The application included details relating to the contingency plan for data collection, in case it was required. The appropriate ethical approval details are included in Appendix iv. The application proved to be straightforward and approval was granted on first submission. However, unexpected issues did arise during the research process, and some occurred following completion of data collection. These are discussed in what follows and recommendations for future research using related methods are made in Chapter Eight: Critical reflections.

Copies of the information sheets (for creators and audience members) and the accompanying demographic surveys and questionnaires are in Appendix vi. When it was felt that the Visitor Feedback Form [VFF] would be a valuable option to gather feedback on the WordPress site, it was emailed to the University's HREC department for approval as it was additional to the method originally anticipated for data collection. This is also included in the Appendix. The terms and conditions of the two

social media platforms, Facebook and WordPress, were observed throughout the running of the exhibitions.

Copyright and data management

Copyright of the creative works remained with the creators and this was made clear in the information provided, as well as being clearly stated on the sites. When I wished to use particular works in conference posters, the appropriate creators were, on each occasion, contacted for permission to do so. No creators refused consent and they were pleased to have additional recognition for their own works and the research project as a whole. As discussed in the method chapters, creators were offered the opportunity to have a 'watermark' placed on the image of their work in order to reduce the chances of it being used elsewhere without permission. Additionally, copyright and terms of use were made clear on both exhibition websites. While it is not possible to determine whether people downloaded content from either site, the conditions of use were certainly respected to some degree, as I was contacted on multiple occasions by academics wishing to use the piece *Pain Without Words* (Exhibit 12) in their own work, for example on a conference poster about peripheral neuropathy. The creator provided consent for this and I made clear on each occasion that the person using the material needed to acknowledge the artist and state that the copyright belonged to that individual.

Data generated remains the copyright of The Open University, as stated on the consent form. The data and consent forms were stored securely, electronically, with password protection and encryption. Participants were informed of their ongoing right to withdraw. Participants were also informed about how their data may be used and information disseminated. Following completion of the research, participants and creators will be thanked for their participation on each of the exhibition websites. To date, this has been done in the Facebook group with clear notifications that data collection has ceased on both sites. Once the thesis is concluded a final thank you and details of findings will be provided to everyone who noted a wish to be updated.

Updates of any articles or output from the project will be disseminated to participants via the exhibition sites, and via email if they have chosen to provide this information on the consent form. Images of conference posters feature on both sites. This was following the request of creators in the Facebook group who commented that they would love to see them. I have also noted details of conference presentations given on the sites.

Online methods

There is often a concern that participants' offline identities may not be consistent with the persona they create online. Mayne (2017) synthesises the literature to show that most users create selves online which are consistent with their offline identities and often form an integral part to the expression of personal identity. Specific issues relating to the use of social media in research, rather than online methods more broadly, are noted by Henderson et al. (n.d.) as being often unaddressed in published literature.

A number of ethical challenges involved in researching with social media are noted by Henderson et al. (n.d., online) as including, among others, consent, traceability, anonymity, ethical obliviousness, obscurity and concern about future privacy-invasive technologies. Mayne (2017) addressed such concerns within her Woolly Wellbeing Facebook group by having specific discussion 'threads' about ethical considerations, including that the participation would be confidential in writing about the group but not within the group and that participants could be traceable. All participants were offered the choice to create a pseudonym but fewer than five chose to do so. However, it is unclear whether the pseudonym Mayne refers to was for use in the group or to be used in the writing up of the research. Given that Facebook has a policy which, though frequently ignored by members, requires people to use real names on their profiles, this was not an option I chose to pursue with participants.

Privacy

There are specific issues regarding privacy with research carried out online. Privacy settings on Facebook, for users/participants and the researcher(s), need to be carefully considered. Lunnay et al. (2015) note that this is to protect participants and the researcher from unethical conduct. While the Facebook group may be 'closed', so that the content is only visible to those who are members of it, this does not prevent people from downloading or saving content, or taking screen grabs. One of the concerns with the use of online methods is that screen grabs²⁰ cannot be prevented, as with any online activity (Cook, et al., 2014). The discussions which Mayne had with participants (regarding anonymity and their participation in her Facebook based research group) demonstrated an awareness and cynicism on the part of members who recognised that 'nothing is truly private' online (Mayne, 2017: 70). Other participants expressed that acceptance of this fact was part of their decision-making process in engaging with the research. Mayne notes that at her time of writing (published 2017) there had been no negative comments to date and that participants expressed a sense of it being a supportive and safe place, akin to my experience with *Exhibiting Pain*.

Privacy settings on both gallery sites allow administrators to approve posts before they are made public. However, the application of these may have prevented the natural growth of discussion if, for example, a couple of people are posting at the same time but unable to view others' posts until such time as they've been approved. Additionally, I believe that my presence would have become intrusive through such an approach to moderation, potentially inhibiting free discussion. As a consequence, it was necessary instead to check the forums regularly to ensure that developments were mediated appropriately. In advance, I agreed with my supervisors that if it was felt that inappropriate posts were occurring frequently, it would be necessary to review and amend this approach, changing to approving comments before they

20 A screen grab is an image created by capturing and copying a computer or smartphone screen at a given time (HarperCollins Publishers, 2019).

become visible to the group. As stated above, no such concerns have been raised to date.

The WordPress blog exhibition was publicly viewable without permission needing to be sought, while the Facebook 'closed group' exhibition required a request to join being accepted by me as administrator/researcher. The choice to feature a 'closed group' exhibition was to provide an exhibition space that audience members actively choose to enter. As such, this was intended to provide reassurance to creators if they had concerns about displaying the representation of their pain. It is important to note that the meanings of terms 'public' and 'private' may be culturally specific and socially-constructed (Giaxoglou, 2017). Therefore, the related privacy setting details for each site were made clear in the information provided and creators had the choice to be omitted from either exhibition if they preferred. No creators wished to pursue this option.

An oversight included consideration of how the content in the Facebook group might be used by other parties. One creator used reflections from the group in an online article about the use of their art to communicate pain. The creator did not name anyone or quote directly but familiarity with the content of the group meant that it was identifiable for members who read both. Indeed, the participant whose comments had generated the creator's reflections commented on their words being used, noting that while they did not mind, it demonstrated concerns about online methods of research. There was a level of trust established in the group and this had the potential to destabilise that. However, all parties were respectful and no offence was caused. This was fortunate and served to highlight to me the complexities of such a research method. At the time of data collection (2016) very little had been published concerning experiences of using Facebook for asynchronous focus group discussions (as opposed to being used for ethnographic or participant recruitment purposes) and this was a drawback for me as a novice researcher.

It was important to have a clear response to concerns about malicious or offensive comments posted on either exhibition site. While the careful moderation of the forums can help to reduce the risks of these occurring, a clear route to express concerns was made apparent to all participants. It is still possible to raise a concern with the moderator (me) by clicking 'report post' as an option on the comment concerned in Facebook. Additionally, individuals are able to send a private message to me on Facebook, or contact via email or telephone, in order to express their concern. These details were made clear in the information sheets provided with the consent forms and on both gallery sites. Through a notice on the sites (as well as in details on the consent forms) participants were advised that any inappropriate or potentially upsetting messages would be removed and their posting rights might be revoked. Also, participants were informed that by taking part they were understood to be agreeing to do so in accordance with these conditions. It was intended that if a comment was reported as upsetting or offensive, if not having being deemed so by me, it would have been necessary to gain information on why it was considered so and assess whether or not to remove it, in consultation with my supervisors, before taking appropriate action. Additionally, the same procedure of reviewing the content would have applied if concerns were recorded regarding individual works and/or accompanying text, or, for example, issues concerning copyright. To date, no concerns have been reported or comments deemed to be of concern.

'Alt text'²¹ was used on the WordPress site (this was not possible on Facebook at the time of data collection). It is unknown whether or not this affected any audience members. Alternative text could have been added in the form of descriptions accompanying each image when uploaded to Facebook but I did not consider this option at the time. It is only at the time of writing, in 2019, that this has started to occur on Facebook more broadly, at the instigation of individual users. Facebook now has an in-built option to add alt-text to images also.

21 Alternative text added to images for screen reader technology

Online methods create specific issues for anonymity and ensuring that participants are unidentifiable, for example in online ethnography (Recuber, 2017). If the text being used for analysis had been written for public consumption, writes Recuber (2017), then it may be appropriate or fair not to use pseudonyms and to provide details to the original source. However, where there is cause for uncertainty, the default convention of maintaining anonymity should be applied (ibid.). In the case of arts-based methods, participants who take photos or create artworks as part of a research process may wish to identify themselves by name as the artists (Cox & Boydell, 2016). However, the images may reveal sensitive or identifying information which ethics boards would argue should be kept confidential (ibid.). Ethical guidance suitable for arts-based health research is limited and not yet flexible enough to allow for the different methods and participants from more traditional research methods (Cox and Boydell, 2016). It is possible that more pragmatic approaches are required to ethical consent in arts-based approaches, for example, once participants have experienced what is involved (ibid.). Or, a greater awareness of ongoing consent is important.

Cox and Boydell cite an example of mural art created by young people with psychosis (Boydell 2013 cited in Cox and Boydell 2016: 85). Several participants are noted as having wanted their names linked publicly with their work because they were proud of it and wished to raise awareness, and hopefully decrease stigma. The researchers expressed concerns regarding identifiability and the need for participants to be fully aware of the implications, such as being identified in 10 years' time when possibly stigmatised while job hunting. The question is posed of what is best done if the key purpose of the research is to empower the individuals and to give them a space to share their stories, as well as to reduce stigma.

While my research did not include the works of adolescents, for whom there are additional safeguarding concerns (Recuber, 2017), there was still an important need to consider the implications of using personal names. It was important to me that the individuals were able to decide what name was used. Of the 23 creators to feature works in the *Exhibiting Pain* galleries, four chose to use a pseudonym, leaving 83%

using their own names. In one instance, an individual who elected to use a pseudonym in the WordPress gallery had posted the work in the Facebook group, using their own name. Before proceeding with the posting in the WordPress site, I alerted them to the discrepancy in order that they be aware that someone in the Facebook group would be able to identify them despite the pseudonym in the more public arena. The individual had not considered this but felt that they were happy to proceed. In another instance, one person using a pseudonym for their art was active in the Facebook group with their own name. However, they did not make reference to the work as being theirs so it was unlikely that anyone in the group was able to make the connection.

While I stated in the participatory information that participants would be deidentified in the thesis and any publications, issues of identification in the writing process have highlighted the complexities involved in this. Given that a number of participants chose to have their names linked to their works on the publicly visible WordPress gallery site, writing about them under a pseudonym became somewhat redundant when their works and connection to them were distinguishable. Consequently, it created challenges in the writing up of findings and has led to a need to consider in each instance whether it is appropriate to make the discussion more generic to avoid any sensitive identification of particular participants. The live status of the Facebook group data has created the same issues.

Participatory methods

As data has been collaboratively generated through the use of found creative works about pain, and an asynchronous focus group via Facebook, issues of control over the data become more complex and need to be re-evaluated in light of participatory research. Cox and Boydell (2016) write, it may no longer be appropriate to retain control over such data and consent may be best obtained in an ongoing process, through the continued participation of those concerned. Although this raises a question of consent for those who leave the Facebook group, while their contributions continue to be present, as they have not requested them to be withdrawn or deleted any participation themselves. Indeed, such a method does allow for clearer ongoing

consent given that participants can edit and delete their own content. Henderson et al. (n.d., online) note that seeking informed consent in social media-based research is complex given that it is

an environment that promotes socially mediated and co-constructed texts, a sense of privacy in the crowd, anonymity through avatars, and in which personal data are increasingly leaving the control of the individual (Henderson et al., n.d.)

In discussing the use of a closed Facebook group for research, Mayne notes that the risks of security and confidentiality were acknowledged and discussed in the group but the gains of forming part of a community were seen as more valuable (Mayne, 2017: 71). Together, the ethical issues of consent in arts focussed and social media-based research is complex and requires a level of pragmatism, combined with common-sense, thoughtfulness and transparency.

Participants

The dual nature of recruitment for this research (as detailed in Chapter Three, Method and Methodology) entailed two types of consent form. Initially, the consent of creators to exhibit their works in online exhibitions was required, followed by consent of audience members to participate in the online discussions, including the right to include quotations (where applicable). Creators and audience participants were provided with information sheets about the exhibitions (please see Appendix vi) before being asked to sign an Open University *Agreement to Participate* form; these documents were made available on the websites and emailed to people who expressed interest in participating.

The possibility of being deemed exploitative of creators' pain was reduced by the self-selecting nature of the recruitment process, with creators volunteering their works for the exhibitions in response to promotion. Creators were invited to participate in the online discussions also, if they wished. It was made clear that participants had the right to withdraw until the publication of any findings; this applied to creators choosing to

withdraw their works too. However, in practice this became more complex as the continued presence of the Facebook group and WordPress blog mean that comments and discussions are still visible. While they can be removed by the person concerned or an administrator (me), becoming aware of this issue during the writing up process highlighted that issues of consent, while ongoing in all research, are particularly complex in regards with internet-based methods.

The *Agreement to Participate* form stated that the participant would be identified in reported findings by first name only. However, unless they used an anonymous account or pseudonym on the website(s), or sent me their comments privately, their name was visible to those able to view the pages. Participants were also provided with the option to be anonymous in the reporting of findings or feature under a pseudonym. These options applied to both audience participants and creators. Mayne (2017) found that a number (no details provided as to how many or what percentage of the group) of participants specifically requested that their names be used in the research. The connection between the use of a name and one's opinion is linked to the concept of empowerment; as Mayne suggests, the omission of names associated with voices in research could be 'disempowering rather than protective' (2017: 72). She adds that this is particularly the case for those participants who identified as disabled, having mental health issues, or being socially isolated. These latter identities being of particular relevance to many members of the *Exhibiting Pain* group, both creators and some audience members. During the analysis and writing up processes it became apparent that pseudonyms and anonymity were more complex to achieve than had been anticipated.

Personal acquaintances

My acquaintances joined the Facebook group following a 'call' on my personal Facebook page (as this meant they were already active on the site and would not need to create profiles specifically to participate) to see if anyone was interested in participating. Consequently, this was voluntary and they self-selected. I ensured that they were aware that I did not require them to participate if they did not wish to and it

was anticipated that they might help get discussions started and then ease off contributions. I had concerns at the time that the decision to involve personal acquaintances meant that my research would be less scientifically rigorous and too subjective. With hindsight the pragmatic decision led to an unanticipated turn in the generation of data and the role of my reflexivity, as discussed in Chapter Four, *The Pained Researcher*.

Those who took an active role in the Facebook discussions, after initial set-up, did so because they enjoyed the discussions and had interests in different topics, such as exhibitions and the artworks, learning more about living with pain, have pain themselves or were academically interested in the method of research. As my acquaintances who joined the group span different aspects of my life and interests this range of motivations is not surprising. Understandably, some acquaintances had a personal wish to see the project prove successful for my sake and this may have been responsible for their initial membership of the group. However, those who remained active participants throughout the data collection period did so because of their own interests. This became apparent because it was clear that the project was gathering data as other (unknown) people took part in discussions and commented on works but some acquaintances continued to take an active role, while others dropped out. I was concerned that no one should feel obligated to contribute and I did iterate this to my acquaintances at more than one juncture (away from being visible in the group). Some of them proved to be entirely inactive in the group so I feel that they did understand that our personal relationship was not going to be affected if they chose not to take part.

Exhibitions

In museums and galleries, ethics are seen generally as guiding values of good practice, enabling a sense of 'moral accountability to the various groups that museums serve' (Gazi, 2014: 1). Exhibitions shape the public's perceptions in many ways, often unintended, through their powerful representations of objects and topics (Gazi, 2014).

What is put on display and the description that accompanies it, are critical in shaping visitors' perceptions of the topic (Gazi, 2014). These comments demonstrate that it was important that the online galleries presented the condition of chronic pain in a way that was sensitive to both creators and audiences but also carried out with openness and respect. By presenting the works, and more broadly the topic and condition of chronic pain, in this way, audience members would hopefully be able to engage with the condition in ways that they felt to be meaningful, shaped predominantly by the creators' own words. This also acts as an additional way to ensure that the participatory methods aim of 'giving voice' to participants is achieved (Mannay, 2016), as far as possible, ensuring that it is the voices of those with pain which are heard, rather than the researcher's or a curator's.

Displaying and viewing pain

It was important to ensure that creators were not made vulnerable through the display of their creative representations of pain (and/or the accompanying text). Equally, it was important to consider the effect on the audience of viewing the works. Daudet (2002) wrote that he should not inflict what he has endured on other people, needing to consider those on the receiving end. The ethics and constructiveness of displaying pictures of suffering is questioned by Edwards (2013) as possibly constituting voyeurism. Chambers' (2010) discussion of responses to an exhibition of facial disfigurement, *Saving Faces*, includes similar concerns.

Audience responses to the *Saving Faces* exhibition are reported to have been 'overwhelmingly positive' (Chambers, 2010: 185), largely because of the awareness of the patients' involvement in the making and exhibiting of their portraits. This raises the interesting point of whether such exhibitions are deemed more acceptable by audiences when there is involvement on the part of the person whose condition is being displayed. As discussed in the Method Chapter, it was originally of interest to know if audience responses to the same creative works varied if situated in different contexts, such as an art gallery, hospital or in a medical museum (for example, the Hunterian Museum at the Royal College of Surgeons). I wondered whether those with

the condition exhibited are viewed as sufferers, patients or people, depending on the setting. This is addressed in part by Chambers' citation of a disabled magazine reviewer who stated that the exhibition *Saving Faces* was very medical, making it 'voyeuristic and patronising' (2010: 187). Where some audience responses deemed the exhibition to be exploitative and akin to a 'freak show', others referred to the act of looking, stating that the exhibition allowed them to look at disfigured faces in a way that would normally be taboo. This is a notion supported by te Hennepe's (2012, cited in Toomsalu, 2012) assertion that a display invites people to stare, reframing suffering.

Sinding et al. (2008) warn of the risk for participants (in this case, the creators) of seeing their struggles (with chronic pain in this context) analysed and objectified. While Sinding et al. make this observation regarding the reporting of findings, for the creators in *Exhibiting Pain* this also applied to potentially witnessing the discussions around, and responses to, their creative works. For all participants, they were able to witness discussions unfold in the Facebook group, including responses to their own comments. While these things occur in other research method formats (such as discussions in a face-to-face focus group), the ability to return to them and see discussions develop over time may have heightened awareness of this for all Facebook group participants.

While discussing arts-based health research, Cox and Boydell (2016) raise the question of whether audiences should be made aware in advance of the emotional or other effects that an artistic work could have. Interestingly, they do not go so far as to use the term 'forewarned,' which would imply an assumption that distress would be experienced. This question is not resolved by the authors who state that the experiences of those who participate in arts-based health research has been largely neglected. The possible distress of viewing the works, and the experience for creators of sharing them, are considered in the findings chapters which follow, and a sensitivity towards the experience for creators is demonstrated by audience members.

Responses of audiences to arts-based health research are generally positive but immersing audiences in difficult, emotionally charged issues holds ethical challenges (Cox & Boydell, 2016). Consequently, Cox and Boydell ask if ethical guidelines should constrain such content or whether challenging audiences is part of what art should be doing. While the framing of pain in creative works allows audiences to ‘have their cathartic moments and leave [safely]’ (Sinding et al., 2008: 8), it cannot be assumed that such formats always enable audience members to distance themselves from the subject matter. Warnings were not given about the potential distress of viewing the *Exhibiting Pain* galleries, although details of relevant support organisations were provided. Given the title of the gallery and Facebook group, and details provided in the information, I believe that sufficient forewarning of content was provided. The online medium also enabled people to leave and return as they wished. Sinding et al. (2008) note that to offer excessive warnings would be to potentially exaggerate the ‘power’ of the works or their content. It might also be perceived as ‘overstating the vulnerability’ of audiences (Sinding et al., 2008: 7).

The viewing of works by those with pain was a concern in case the focussing on pain or sensitive issues of personal relevance was distressing for this group. For example, Sinding et al., (2008: 8) note that the potential of creative representations to ‘undermine or bolster hope’ is a central ethical concern. There was the possibility that viewing the works could bring hope and comfort through a reduced sense of isolation. However, it could also lead to a sense of despair, being overwhelmed, or increased focus on personal symptoms and concerns. Findings demonstrated that those with pain who responded to the works, found it a helpful and comforting experience. This is reflected upon in Chapter Eight: Critical reflections.

While it is important to consider distress in all research, there is a need to distinguish it from harm. Sinding et al. (2008) discuss that the distressing effect of a drama representing women’s experiences of breast cancer was part of how it achieved resonance for audiences. Response to viewing the production rarely included a desire not to have seen it, despite the distress evoked at times. Instead, audiences spoke of

the realistic portrayals and wishing for friends and family to see it. Consequently, the benefit and distress of viewing the production were entwined. Sinding et al. note that this means while efforts to minimise harm are required, the elimination of distress may counter the 'integrity and effectiveness of many artful representations' (2008: 10). As such, it may therefore be the distress caused by viewing creative representations of chronic pain that leads to them being effective in eliciting understanding.

Practicalities for the researcher

Lunnay et al. (2015) refer to their research utilising Facebook to communicate with participants, make arrangements and increase retention. In doing so, they become Facebook friends with the participants and were therefore able to see status updates and other details (the participants could have blocked these from their view if they changed privacy settings but this is another example of how people may not think about the public-private nature of research using social media platforms). I was conscious of a need to balance appearing friendly and approachable, so used my own Facebook profile rather than setting up a separate one for the research. This meant that I was then conscious of what picture was being used on my profile and checked the privacy settings on my details.

However, one participant attempted to 'add' me as a Friend. I messaged her to say that while data collection was taking place this would not be appropriate but ensured my message was friendly in tone. Following this, I amended my own privacy settings to ensure that to request my Facebook friendship, we had to have a mutual friend on our profiles. While this would not necessarily limit everyone, it worked to reduce the number of times I might have had to encounter this situation (there were no further instances). However, there is potentially an inherent conflict in having personal friends and acquaintances participating in the research but not accepting the Facebook friendship of a participant. I justified this through the established relationships with my acquaintances and an acknowledgment of the potential conflict in also using them as

participants. I was not comfortable with forming friendships with people who were first and foremost participants who I had not met in person. I felt that this was potentially exploitative of them or me and I was keen to maintain professional boundaries, most particularly while data collection was taking place.

As data collection proceeded, and the group continued beyond that point, some of the participants have become to feel more like close acquaintances. I have not crossed the boundary into becoming Facebook friends with them as I feel this would be potentially exploiting my position as a researcher who held power in the original dynamic of our interactions.

Linked to the issue of forming friendships with participants on social media, is the opposing issue of responding to situations which are offensive or potentially abusive. To date, I have not located literature on this issue but it was one which I encountered. As a consequence, it was necessary for me to block the person concerned from the *Exhibiting Pain* group on Facebook and to block through my personal account to ensure that they were not able to look me up or contact me. However, this would not prevent them using a different profile in order to do so. I also needed to block them on Twitter (which I had used to promote the research) and WordPress. While this situation was resolved relatively quickly there is the potential for particular emotional and psychological harm to researchers through the use of online methods. This is discussed at greater length below, in sub-section 'Encountering a difficult participant'.

Having participants from across different global time zones entails frequent interaction at different times of day occurring. While this can help to increase activity and engagement, it risks delays in picking up offensive or upsetting comments (unwarranted concerns to date). It also creates challenges for the researcher in

monitoring and managing comments (Mayne, 2017). Additionally, it can create difficulty in switching-off from the research and work.

Encountering a difficult participant

As mentioned in the previous chapter, sub-section 'The vulnerable researcher', I encountered a participant who caused me some considerable distress. The incident occurred because they were unhappy with the text accompanying the artwork, having forgotten that it was the text provided personally by them. The creator had said that the text may need editing and reducing and was happy for me to do so. However, the only changes I made were to correct one minor typo and insert two spaces to break up the passage for ease of reading.

After sending an email to all participants to 'announce' that the galleries were live (and that the creators were welcome to join the Facebook group), the participant sent multiple angry emails and left an answer phone message with threatening language towards me. Persistent emails included demands for the text to be amended immediately or I 'would regret it', threatening reports to the media. They also called into question my professionalism and abilities. The person was informed that there were some ethical considerations to be discussed with my supervisors and that it might be best to remove the work from the site. Consequently, the individual replied that it was unethical to take the work down from the sites as it was important that people heard about the damage (allegedly) caused by certain medication.

These messages were followed by further emails to all three of my supervisors and others as it was escalated higher in the university. It was apparent that the participant was impatient for responses and prone to impulsive, rather than considered, reactions. The individual made repeated and persistent attempts to interfere with my work, despite my attempts to mediate the situation. Consequently, the work was removed from both gallery sites, in consultation with my supervisors, and I had to block the

individual from the Facebook *Exhibiting Pain* group, my personal Facebook profile and on Twitter. These particular actions were taken as the person had attempted to 'Friend' me on Facebook (I think as a way to communicate with me) and I was afraid of the same occurring via Twitter.

Finally, the case was taken by the Faculty's Director of Postgraduate Studies to the university level office for Research, Scholarship and Quality. I provided details of decision-making processes, HREC approval documentation, correspondence with the individual, copies of the information sheets, the person's completed consent form and records from supervision. I was grateful to be informed that I was found to have acted according with the University's expectations and with integrity. I did not seek details of the final dealings between the individual and the university.

In my naïve eagerness to 'give voice' to those with chronic pain I failed to give due consideration to the content of the text. With hindsight the content probably was not appropriate as it included allegations about damage caused by a particular type of medication, though the drug itself was not named in any text accompanying the work. However, I was aware that this person's work was featured elsewhere online with the same (and additional) allegations so it was not without precedence or other sources. It was also clear on the gallery sites that text was provided by the creators, so the allegations were not something The Open University was supporting. Nevertheless, the experience certainly provided a steep learning curve for me and taught me to think more carefully about the implications of each action. Indeed, this does raise the question in ethical considerations about the balance between giving voice to participants and the need to weigh this against the individual researcher and institution's needs. It also demonstrates the need for caution in carrying out online research as the researcher becomes accessible to participants in different ways, for example, via social media. While I am personally attentive to securing my privacy settings on social media, it did highlight this as a possible safeguarding risk which may need to be considered in ethical guidance. This is where using an account for the

project itself, rather than my personal Facebook account, would have been beneficial, leaving me to feel safer accessing Facebook through my personal account.

Conclusion

This chapter has demonstrated that there is a need to develop evidence-based ethics in the field of arts-based health research, using empirical studies rather than based on ethical values alone (Cox & Boydell, 2016). This is important to increase awareness of how such research is experienced by participants, helping research and creative practice to develop (Cox & Boydell, 2016). In their experience, write Lunnay et al. (2015), the ethical complexities of social media centre upon the concept of what is public information and what is private. This is an inherent blurred distinction within social media and traditional expectations about privacy need to be updated to account for it, while age differences may also need to be considered (ibid.). For example, Livingstone (2008, cited in Lunnay et al., 2015) demonstrated that young adults' definition of privacy (in the context of social networking sites) is not linked to certain types of information being divulged but is focused on having control over who knows what about you. To address this concern, Lunnay et al. suggest that researchers educate participants about different interpretations of privacy and the range of ways in which information may be gathered and used publicly, despite best efforts to follow ethical procedures. Mayne (2017) had facilitated a discussion between participants about privacy and understandings of this. She argues that her Woolly Wellbeing Research Group consists of 'real people who perceive themselves to be a community', and therefore 'there can be no difference in the ethical approaches to managing their data simply because it was generated online' (Mayne, 2017: 73). However, I believe that the use of online methods generates idiosyncratic issues which do need to be considered within the appropriate context.

In this chapter I have demonstrated some of the idiosyncrasies in the ethical considerations of carrying out this research project. Taking account of online methods, arts-based and visual methods, copyright considerations, the use of anonymity (or not)

Chapter Five: Ethical considerations

of participants as well as the experience of responding to a difficult participant. The following chapter moves to explore the findings in relation to how life with persistent pain is expressed creatively as well as the broader use of creativity by people living with the condition.

Chapter Six: Creating and expressing pain

Introduction

This first findings chapter explores the way in which pain is seen to be expressed in the creative works, drawing on aspects of the themes identified in the 'Representing Pain' category of Figure 4, above. The discussion will take account of how language is used and the aesthetic content of the works. This will differ from the following findings chapter which places an emphasis upon how such content is 'read' by audience members and the response when viewing the works. In doing so the second findings chapter takes a broader view on participation in the research, exhibition experiences and interpretative process. Discussion in this chapter (Creating and expressing pain) includes consideration of the viewing of works but with a focus on the elements used by creators to express their pain, and how these were received by audience members, such as the aesthetic devices used. In this first findings chapter, the use of creativity and the expression of pain are the focus of discussion by exploring the communication of chronic pain as it appears in the research data, both by creators and those with pain, and how participants without pain refer to it. It will be demonstrated that it is possible to express the experience of living with persistent physical pain through creative means. A creative element added to the communication process is shown to facilitate a more comprehensive, multimodal, representation of an individual's experience. The audience which creators had in mind for the works will be discussed and the findings will be used to highlight a public-private 'dualism' which exists for those living with chronic pain, seeking public awareness and validation while managing a private, subjective and invisible condition. I begin by considering the nature of creative activity and what it means to the participants of *Exhibiting Pain*, together with how this relates to living with chronic pain, as this sets the background to the discussion which follows.

Creative activity

The nature of creativity was discussed in the Facebook group with regards to how participants understand it as a concept, as well as how it relates to pain. Creators' responses, to the question of what creativity means to them, show that it is understood as a broad term. One creator [C] mentioned the use of the imagination 'to express something in a new or different way' (Dylan, C). Leslie (C) comments that they had previously thought creativity was 'about being talented and to produce an aesthetically pleasing piece of art'. Leslie adds that a pain and fatigue management clinic had taught them to be 'creative within my limitations'. This implies a changed perception of what being creative entails, with less emphasis on the perceived quality of the final piece created. This related to an understanding of whether or not something is 'art' which is also touched upon by Mel (Pained audience member [P]) who noted that they journal 'doodle drawings', adding that they 'would not call [their] drawings art, more an extension of [their] thoughts'. Another creator, Frankie, writes of creativity as a way of experiencing new situations, stating that some experiences with chronic pain are 'dark/difficult and it is a challenge to widen our ideas of what creativity means'. Frankie (C) adds that life 'in this new world of pain' means having to try things, fail, and try something else. This implies that creativity is needed in adapting to a life with chronic pain and to manage the condition. Bobby (P) stated that those in the Facebook group

persist, and create, rather than dwelling [...] turn [pain] into something beautiful or disturbing, but turn it in to Something [sic].

By stating this, Bobby (P) demonstrates a belief that creative activity has the effect of transporting someone, mentally, from their pain or to absorb their thoughts sufficiently to shut out pain, akin to the benefits of creative flow²² identified by Reynolds and Prior (2006) when considering the art practices of women living with cancer. In the process, the act of creation is a transformation of the pain into something new. The transformative process attached to creativity is also

²² 'Flow' describes the experience of a person being entirely engaged in a task, to the extent of losing track of time and demands outside of that activity (Gauntlett D. , 2011)

demonstrated by Angel (P). The act of drawing their hand helped Angel to move away from viewing it as deformed and ugly, stating 'the sketch put it back in perspective'. Consequently, the act of creation helped to re-evaluate a physical difference, facilitating an acceptance of it.

Earlier, in Chapter Two's literature review, creativity was defined as a 'process and/or activity which produces something new that is effective in eliciting emotional responses'. This appears to accord with creators' ideas above and those provided by other participants. Creativity was defined by Charlie (Non-pained, personal acquaintance [NP-PA]) as the re-working of something into a new idea or form, or creating from scratch. Also referring to it as an 'opportunity to let your brain escape the world and gain satisfaction from the magic of simply making something' (Charlie, NP-PA). Another NP-PA, Riley, identified creativity as being 'much broader than most people think'. Both Charlie and Riley participate in creative activities and have an interest in visiting museums/galleries, as well as working in related arts fields. It is possible that a broad acceptance of the definition of creativity links to their personal interests and areas of employment. Other responses to this question were provided by creators but not by any audience members who had stated no leisure or work connection to arts activities. It is possible that other participants did not feel they had the appropriate knowledge or experience to answer the question, or felt that it was not relevant to them. It is also possible that they felt they had nothing to add to the comments already made.

In order to understand the motivations behind creators' use of creativity to represent their life with chronic pain, I asked if they had a prior interest in the arts, before the onset of the condition. Only one creator stated that they had not had a prior interest while the remaining creators, who did all have an earlier interest, expanded their responses to some extent, whether simply stating 'always' or 'since childhood', or providing more specific details about their artistic experiences. There were no discernible correlations between the duration that someone had pain and their wish to represent it creatively, or their means of doing so. The ranges of experience and

interest were broad. For example, some had a childhood interest in needlework or art, for others it was writing and a few had pursued professional training and employment in creative industries (five stated that they had received training or held qualifications in an arts field). The reasons that so many creators in this research study had a prior interest in the arts becomes clearer when the motivations are explored of why they began to use creativity to express their pain. For these individuals, creativity or art is described as their 'natural language' (Hayden, C) through which to communicate and an activity in which they had held a long-term interest. As some creators specified that their prior interest had been during childhood (rather than 'since' childhood) there is an implication that the interest may have lapsed for a period of time. However, it was also significant enough to them for it be considered worth including in their responses to this question.

Creators were asked about their motivations for using creative practices to express life with pain. The most common reason, given by 48% of creators, was to express or release emotional pain and mental distress. More than one reason was often provided, including that creative activities were described as a pain management tool (four creators mentioned this). Responses are illustrated in the pie chart in Figure 9, below. Creative practices are also described as a way to communicate life with chronic pain (39% of creators); five mentioned that art was a natural form of expression for them. Two creators provided no explanation while another six gave responses which were categorised as 'other' (such as for a university qualification); two of these made reference to depicting life as they see it, including their pain:

it is automatic to somehow pain to be represented in my work,
either physical or emotional. Either my own pain or pain in
general [sic] (Jamie, C).

Two creators stated that they 'always have' depicted pain, without adding an explanation as to how or why. Hayden (C) describes that art was a 'lifeline for expression'. These comments relate to the description of art being an innate language, which was provided by a number of participants, in the sense that the act of using creativity to show their pain is inherent to them. Additionally, art was commonly

described by creators as either an easier way to express themselves and/or for others to understand. As George (C) wrote, 'pain is so difficult to express in words, a physical image worked better'. Although it is unclear if it is the image itself that succeeds in communicating the pain message or the multimodal combination, with accompanying text or narrative.

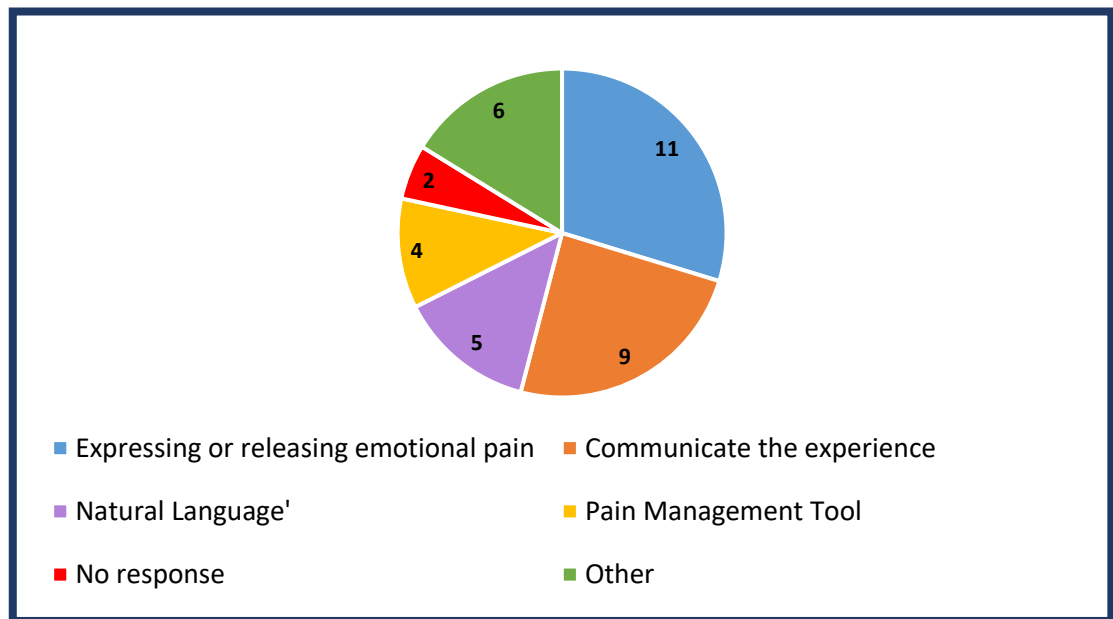


Figure 9 Creator Motivations in using creative methods to express life with chronic pain

Pain management, as a reason for representing their pain creatively, was cited by four creators. However, the use of the activity as a coping mechanism for emotional pain was the most common reason provided. A few of the creators refer to using art to express their 'emotional pain' or they made specific references to using it to cope with depression and mental distress. The contrast to physical pain is provided by Jordan (C) who wrote that art helped them to release the negative feelings about their life. Leslie (C) stated that using an art journal had helped to 'relieve frustration and suppressed anger, and my hopelessness.' Sam (C) notes that they find themselves journaling when their pain is at its worst, which suggests an element of relaxation or catharsis may be attached to the activity. Similarly, the only creator who did not have an interest in

creative activities prior to the onset of their pain, noted that their reason for participating in such activities was 'to ease the mental and physical – a release of feelings' (Parker, C).

Equally, art and creative hobbies were described as providing distraction from the pain and to help the individual to personally understand their own emotions, as well as supporting those around them to do so. Bobby (P) stated that all of their art is to help them to work through pain and anxiety, 'because the act of creation excludes worry', going on to say that the focus on the lines and colours created leaves no room for consciousness of the nausea and pain. Bobby (P) also states that pain is the motivator behind all their art, 'in order to ignore or create despite the pain.' These references to distraction are appropriate as this is a recognised pain management technique (Butler & Moseley, 2012).

Reflecting on the process of creating a work, Angel (P) noted that often they do not have a clear vision when painting their pain and it is only afterwards that they recognise what 'was going on.' This suggests that for some people the act of creation as a planned communication of pain may be somewhat accidental. However, it does not necessarily follow that what is depicted is not a valuable or accurate expression of life with long-term pain. Works are kept as a 'private diary' for Cam (P); this shows that the creation of works may act as a Pain Diary or journaling tool. It may also form part of a cathartic process through the externalisation of the pain. George (C) describes the use of creativity in this way, stating that it helps to 'put the pain outside of my body so it doesn't consume my mind'.

The use of creative activity for catharsis and pain management is picked up on by Sam (C) who writes that their 'pain art is merely a form of personal therapy.' The use of the word 'merely' is of interest, implying that this is not a sufficient role for the creation of art or that the concept of doing something for their own therapeutic purposes is not as significant as if they were to use the art for other purposes. The term 'pain art'

suggests that they do create other art, not linked to their pain, and that they feel it is possible (and appropriate) to distinguish between such works. This might be deemed in contrast to Jamie (C) who noted that all of their works are connected to their pain in some form or another. Jamie notes that they 'observe life in general' and that it is therefore 'automatic' for pain to be represented in their works in some format, even if not autobiographical, as 'pain is all around us, for everyone.' Cam (P) wrote in the Facebook group that they were trying to break a current 'creative block,' adding that the 'pain has gotten the best of' them. This suggests that the pain led to a block in creativity which is implied as being the best aspect of them, demonstrating its importance to their sense of self and health.

Angel (P) refers to a poem in the Facebook group as a

more creative way of expressing what was my turning point to
stop waiting to get better and just get on with living again.

This suggests that the creative presentation of this process or feeling was valued more than a narrative expression of it. It also shows the perception of a need to cease seeking a cure or recovery, in keeping with principles of pain management programmes to focus instead on managing the condition (The British Pain Society, 2013). Having previously been an artist, Cam (P) could no longer sit at a drawing board and so learned computer skills, describing this as a silver lining, helping them to cope. Lou (P) remarks that 'mindfulness through art [provides them with] a sense of inner peace and strength to cope with pain', while Angel (P) refers to the creation of works as being like a meditation. Tatum (C) noted that art 'has been a way of starting to come to terms with the massive change in my life'. Jordan (C) wrote,

after my accident I found myself creating a different kind of art
[...] it opened up my creativity to a whole new side of my soul.

Jordan's statement demonstrates a change of self and that this experience has the potential to affect the art produced, consequently showing the scope for expressions of self, pain and identity. Leslie (C) reported that the use of art on a daily basis has changed their perception of their condition positively. Together, these comments

Chapter Six: Creating and expressing pain

illustrate the ability of the creative activities to help people come to terms with their pain experiences.

The topic of future works arose in audience responses to the works. Bobby (P) noted that while pain was not previously a feature in their art or writing, they had now decided to 'make pain a subject or focus of my works to come', after joining the Facebook group. Jude (P) stated that they had been inspired to start making again and that the works had helped on their 'journey of learning to accept and inspect my pain without trying to battle it'. In response to *Wascally Wee Willy* (Exhibit 1, p. 144), Kelsey (C) noted that the discussion of 'mutancy' in the accompanying text had made them wish to explore, in future works, ideas around terms that they experience as undesirable, such as 'cripple' or 'disabled'. Via the Visitor Feedback Form [VFF], Jo (P) noted that since viewing the exhibition they now wished to think about doing a photography project on their own pain, as they already participate in the activity.

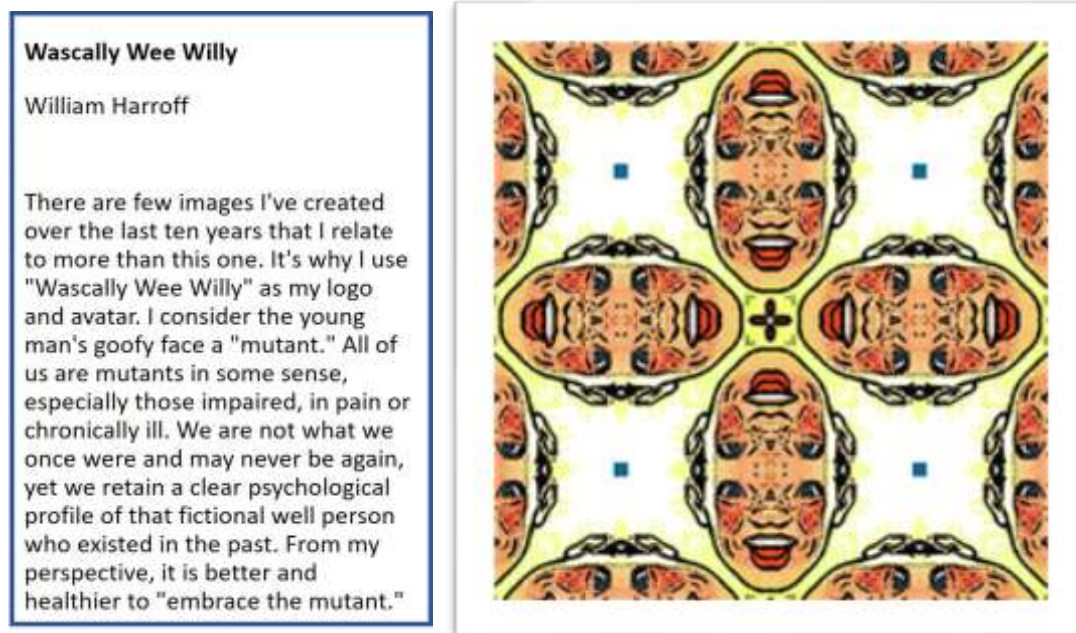


Exhibit 1 *Wascally Wee Willy*

It has been shown that the concept of creativity itself, and the activity, have broad meanings for all participants. The activity of creating has been shown to help acceptance of pain or 'abnormality' of body and create a cathartic outlet. I move now to consider how pain is expressed through the use of language and the aesthetics of the works (for example, use of colour). Additionally, this will consider who (in terms of an audience) the creative expressions of pain were intended for.

Expressing pain

Language

Metaphors can be a creative way of using language to demonstrate that a pain is sharp 'like a knife' or akin to 'being stabbed'. In describing pain this way, the individual draws upon a common understanding of what such a pain may be like. While many people are likely to have experienced minor incidents with a kitchen knife, and use this to imagine the sensation of being stabbed, most people will not be familiar with the actual experience described. However, this does not appear to limit the amount such metaphors are used or their value in explaining a pain sensation, given that the majority of people appear to understand what is meant by it and the associated pain being described.

Biro (2010) notes that health professionals are uncomfortable with the reliance upon metaphorical language when describing pain, while patients often want more of it, rather than less. Stewart (2016) notes that metaphors have been argued as oversimplifying human suffering. Consequently, Biro (2010) argues that the use of the FACES pain rating scale may be preferred with its focus upon intensity of pain as opposed to the language-based descriptors used in the McGill Pain Questionnaire. This may help to address demands for pain relief but be less useful for diagnostic purposes, given that different descriptors are appropriate for muscle pain, for example, than those used to describe neurological pain symptoms. Consequently, it appears that a creative use of language can be effective in eliciting a level of understanding of the

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pain being experienced. However, a restriction to linguistic based assessments may be that they limit a full understanding of both intensity and sensation descriptions of pain.

‘Sufferer’ is a word used regularly when referring to people who have chronic pain. It is a term which I feel strongly about (Main, 2018c) and is rejected by others who believe that they ‘live well’ with pain, accepting the condition as an aspect of their life or identity. de Montalk (2019) discusses two differing translations of Daudet’s *In the Land of Pain* (2002), noting that the translators differed in focus. The first translator, Milton Garver, entitled the work *Suffering*, publishing it in 1934. Julian Barnes’ 2002 translation has the title which focusses upon the ‘land of pain’. de Montalk notes that in Garver’s translation, the metaphor is used of ‘an orchestra of suffering’ but Barnes refers to a ‘band of pain’. Whether the differences in focus – on suffering or pain – is due to the period in time when the translations were published, or due to the perspectives of the translators, is unclear. However, it serves to highlight the different focuses that may be given to the experience of living with long-term physical pain. Consequently, the views on the concept of ‘suffering’ by creators and audience members was of interest to me.



Exhibit 2 *Painabstract 02-2010 gouache medium*

Painabstract 02-2010 gou medium

Hannemieke Stamperius

Pain-abstracts are inner landscapes, physical as well as psychological. They may be a bit scary – suggestions of skin, blood vessels, the blueish green of organs, rampant proliferation in ink – but, because not only the paining but life itself as well asks for harmony and balance, they have those characteristics as well (I hope).

Many people, and more as one grows older, have to live in constant pain. One of my strategies is, to study the pain carefully and lovingly, without any thoughts or feelings about the pain, trying to find the truth of the pain itself – and then, balance is possible. This is what I try to make visible here.

The term 'suffering' was used often by those participants who do not have chronic pain, when expressing comments about someone's pain. This varied as to whether it was in reference to knowing people who have persistent pain (Charlie, NP-PA) or in relation to the depictions of the condition (Billie, NP). There is also an assumption that those who live with pain are suffering, for example Jac (NP-PA) stated that the colours in *Pain Abstract...* (Exhibit 2, p. 146) provide a sense of 'unhealthy skin', which elicits a sense of 'discomfort and suffering'. Taylor (P-PA) refers to themselves as suffering in response to *Do you see what I feel* (Exhibit 3, p. 148), noting empathy with the work because of also experiencing chronic fatigue syndrome. In response to *My Reality* (Exhibit 4, p. 149), Taylor (P-PA) states that they 'suffer' in response to particular symptoms of their condition.



Do You See What I Feel

Dana Harrell-Sanders

Oil on canvas
20" (H) x 16" (W)

My painting represents those that suffer from fibromyalgia/chronic fatigue syndrome. A person suffering with the disorders seem so healthy on the outside that others have a hard time perceiving what's going on inside.

Exhibit 3 Do You See What I Feel

In the Facebook group I asked members: 'Does someone 'have pain', 'live with pain', 'live in pain' or 'suffer with pain'? Or some other phrasing?'. The last option of 'some other phrasing' was included for those who use a different way of describing how they live with pain. While the first comment received was from a new member to the group

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who provided their personal illness narrative and present difficulties, others picked up the intention to ask about the semantics used around having pain. This generated discussion about the concept of 'suffering' and alerted me to the use of the term in the data as a whole.

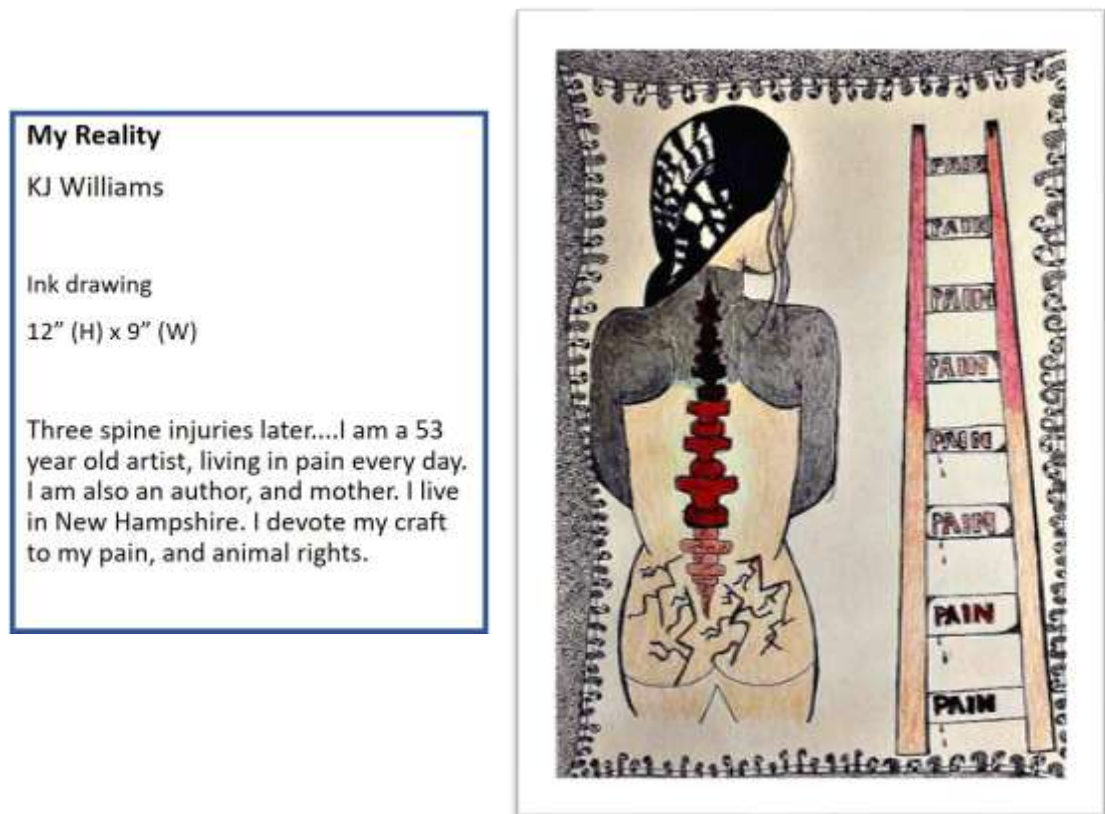


Exhibit 4 *My Reality*

In response to the Facebook question, Jude (P) stated,

I feel it is mine, and I need to embrace and accept it, in order to live as well as can be side by side with it. In another way, it's an experiencing I am having, and perhaps I don't want to 'own' it [sic]

In agreement with the sentiments expressed above, Angel (P) stated that 'anyone in [chronic pain] is suffering, it's part of the shitty deal, but life does go on'. This would imply that suffering does not mean an end to 'life' but continues in spite of, or with, pain. Raj (P-PA) wrote that 'a person cannot say that someone else suffers from pain, as only the person with the pain can decide'. This opposes the biomedical approach of

assuming that someone with pain must be suffering and in need of treatment. Sydney (PU-PRO) stated that they use the expression 'having a pain experience', adding:

these words are enough to catch someone's attention about what pain is - and then we can talk about pain being an output of the brain. They get to define the experience they're having and the story attached to it

Here, Sydney is using this terminology as a way to open discussion with patients about the nature of pain, enabling them to define how they experience it and their story.

Dylan (C) commented that they try so hard to avoid saying it that 'I don't think I have a common phrase'. While this may raise questions regarding acceptance and 'living well' with pain, it also touches upon another important issue in the communication of chronic pain – the topic of privacy versus choosing to express pain *experiences* publicly, as discussed below, sub-section 'Public-private dualism'.

Aesthetics

The analytical code of 'aesthetics' was applied to data concerned with colour, imagery, materials, textures and style. This might be in terms of the impact and effect of these features or how they relate to the portrayal of the subject matter. Before discussing the use of aesthetics in the expression of pain, it is first useful to provide some background context to understanding and interpreting colour. A psychology of colour emerged from the late nineteenth-century onwards, writes van Leeuwen (2011). Such psychologists, like later poststructuralist philosophers, perceived colour as a 'highly immediate, individual feeling' (van Leeuwen, 2011: 9). Experimental studies were carried out showing blue to be calming, for example, and red as eliciting excitement (ibid.). van Leeuwen notes that despite psychologists' efforts to identify universal meanings of colour, these do not appear to exist. Instead, there are multiple conventions, codes and uses of colour within different limited contexts, as demonstrated by Pastoureau, 'colour is first and foremost a social phenomenon. There is no transcultural truth to colour perception' (Pastoureau, 2001, cited in van Leeuwen, 2011:15). Consequently, it is helpful to consider how colour was used in the works in order to discern if there were any identifiable patterns to its use to express pain.

Relating to the discussion above about understandings of colour, Chris (NP-PA) comments on having a 'preconceived perception' of it, connecting this to a natural and inherent response related, for example, to the red of poisonous berries. Chris notes that this may be a cultural understanding of colour – recognising some learnt and socially constructed values inherent to these interpretations. This understanding accords with van Leeuwen's (2011) understanding of colour as being defined by society. However, Chris remarks that 'blood, inflammation, bruising, etc. all have very natural visual signals', implying a biological and innate understanding of colour as signifier. Socially constructed ideas of colours as signifiers is highlighted by Stevie (P) who notes,

I was expecting that pain may often draw in red... in spite I have synesthesia²³ and really don't feel that my pain have any colour [sic]

There is an implication in Stevie's words that colour associations are something they usually experience but that they do not associate particular colours with their own pain. However, Stevie retains an expectation of red being used to depict pain, demonstrating the learnt signification of this colour. It would be interesting to know if Stevie experiences colours attached to words about pain, as opposed to thinking of their own pain sensations – whether their subjectivity plays a role in the perception of colour linked to pain. While the topic of synaesthesia and pain is outside the scope of this research, the comment emphasises the learnt role of colours as signifiers of particular sensations or emotions.

Attitudes to coping with pain are discussed in response to the works, drawing on content and colours in doing so. A link between colour and hope is made in response

23 A condition entailing the 'merging of sensations'; for example, hearing words may cause taste sensations, or letters or words feel coloured, such as 'A' being red (Simner, n.d.).

to a work shared by an audience member with pain²⁴. Mel (P) commented that the yellow dots featured in the work 'create a feeling of warmth/hope/healing', Lou (P), who created the work, said that they loved the interpretation of the yellow 'representing hope and healing'. Jo (P) also commented that lighter colours, to them, reflect their hope for continued improvement. Sam (C), on viewing *Phoenix* (Exhibit 5, p. 152), empathises with the grey area of the work but comments that they are impressed and given hope by the creator of the work being able to 'fly again'.



Exhibit 5 *Phoenix*

24 As this work was not part of the original set of exhibits, and was shared voluntarily by a participant in the closed Facebook group, it is not reproduced here.



Relating to the use of colour, comments included mention of the use of blacks and reds which audience members felt appropriate to the subject matter, 'red feels like a pain colour' (Kim, P-PA). The same audience member (Kim, P-PA) commented that the more colourful works 'were pretty but didn't communicate an experience of pain to me'. Suggesting that preconceptions and understandings of colour linked to a personal understanding of how colours may represent pain symptoms and experiences. Charlie (NP-PA) referred to 'harsh colours' and 'sickly hues' as helping to connect them with the artist's feelings. The use of these adjectives suggests that the pain experience is being interpreted as harsh and sickly, with these particular colours acting as signifiers²⁵. Jac (NP-PA) commented on the colours portraying a 'feeling of unhealthy skin, which transmits some idea of discomfort and suffering.' This indicates that respondents connected certain colours to sickness, illness, suffering and pain.

²⁵ A signifier is a symbol, object or other item which represents a concept or meaning

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Mentions of depression are associated with the use of the colours black and grey, while red is linked not only to sensations and severity of pain but also with anger and chaos. Works with brighter or a range of colours were seen as representing lower levels of pain, they were also understood, as mentioned above, as possibly showing hope and coping with pain (Kim, P-PA). Blue was noted as a calming and comforting colour, together with green (Angel, P; Charlie, NP-PA). These observations about the use of certain colours to express emotions, mood and pain were not disputed between participants, suggesting a level of consensus, despite possible differences between language and cultural backgrounds.



Figure 10 *Pain Management* by Susanne Main

As discussed in Chapter Three: Method and methodology, I posted a piece of textile art in the Facebook group upon first opening it. The work is shown in Figure 10 (p. 154) and presents my pain management techniques. Of particular interest to me was that I had not put any conscious consideration into the chosen background fabric. It was a pragmatic choice based on what I had available which was large enough and seemed to contrast effectively with the brown of the medicine bottle. However, this background colour was noted by Stevie (P) as being 'too sweet' to be used in a work about pain. My limited experience and skills in this creative activity were certainly relevant (in that I had not considered colours or textures); however, Stevie's comment also demonstrated that meaning may be interpreted and/or attributed where it is not intended. The interpretative process of the works is discussed in the following chapter but it is worth highlighting that this demonstrates that the selection of certain aesthetic features (such as particular colours), to express particular elements of the pain experience, may result in unintended interpretations.

While many connections were made between colour and emotional responses to pain, there were also associations made with sensory experiences. For example, the 'sharp stabbing' and anger of red, the 'dull ache' of grey and 'total desperation' of black (Jem, NP-PA). The word 'colour' is used in reference to works that include an array of colours such as blues, greens, yellows; for example, in *How do you feel* (Exhibit 6, p. 156). This implies a contrast to when specific colours are noted – usually red, black or grey. Colourfulness itself is seen to be expressing a contrast to pain. Angel (P) wrote, in response to the work, that when you find something which helps, 'the colour comes back to the world. Then it stops working and the colour leaves again.' *How do you feel* provoked a few reactions about the use of colour which may be due to its unusual nature in the collection, featuring a range of colours in a somewhat abstract design but retaining some figurative elements. One response included the interpretation that the colours (featured in blocks) 'could be the succession of moments – some of them are calm, joyful, some [are] dark and distressed' (August, NP). This interpretation can be used as a metaphor for life but a connection can also be drawn between the experience of pain fluctuating and the fragments of different colours in the artwork.

How do you feel
Helen Harley



Exhibit 6 How do you feel

Stevie (P) notes that the use of 'light and very bright colours' was interesting. No further comments are added to expand upon this remark but it illustrates that people have inherent assumptions about the use of colours to show pain, implying surprise at alternative colour choices. Jo (P) mentions the use of dark/light also. Jo links darker colours to increased pain levels and lighter colours to reduced pain and 'hope for continued improvement'. Bryce (P) noted that the colours create 'focal points of the effects of pain'. Consequently, the expression of pain through the use of particular colours and tones is shown to be effective in engaging audience members though may not be received as intended by the creator.

Alex (NP) observed that the *persistence* of chronic pain is the hardest thing to understand. Alex noted that the 'stark' use of red and black were not helpful with this

but the ‘more gloopy sombre [works] convey the persistent rundown monotonous greyness of constant pain a bit better’. This is interesting as assumptions about the works included surprise that the focus is less about sensations and more concerned with the emotional and mental impact of living with persistent physical pain. It suggests that in understanding the nature of living with long-term pain, a movement from the graphic impact of stark colour choices and imagery may be helpful to achieve a more nuanced expression. Pat (P) remarked on the frequent use of red and black, observing that they use these in their own art, as well as ‘the absence of colour to reflect my pain’. Pat suggests that the ‘drama’ and dominance of such colours is the appeal,

since pain overwhelms our lives and sense of self, perhaps that is why we are drawn to colors that dominants our senses [sic]

Again, this raises the question of why creators make certain colour choices and whether audience members interpret these accordingly. This question relates to issues of interpretation and possible ‘mis-interpretation’ which is discussed in the following findings chapter, sub-section ‘Interpreting works’.

The conscious choice to use textural devices is demonstrated by a creator in response to my query about the technique used in a particular work. The creator stated that they had used a particular technique to ‘give an impression of hundreds of points of pain on the body’²⁶. Texture was remarked upon in my own example piece, *Pain Management* (Figure 10, p. 154), when Phoenix (C) responded to the softness of the fabric as evoking thoughts of ‘receiving nurturing’. Consequently, the texture (though viewed on screen) was successful in portraying a particular message – however accidentally this occurred in my piece, through the choice of textiles.

26 Unreferenced to reduce identifiability of this person



**#23 poverty transmuted with
God into a Miracle of Prosperity**

Jay Kyle Petersen

Mixed Media on illustration board
1989

Healing poverty from disability,
unemployment to gainful income
doing art and what I like and
love=my art, film, writing,
speaking and social work.

Exhibit 7 #23 poverty transmuted with God into a Miracle of Prosperity

The abstract nature of the content of some works was commented upon by audience members. For example, by expressing a preference for more 'illustrative' works (Charlie, NP-PA). The success of a work to communicate pain is remarked upon by Jac (NP-PA) in commenting that although *Wascally Wee Willy* (Exhibit 1, p. 144) did not

elicit an understanding of pain *per se*, it made the viewer very uncomfortable and aware that something was not 'right'. Jac felt that this made it a very successful piece of work, although this may also be linked to personally liking the illustration and feeling that it was 'really well executed'. Audience members (with or without pain) noted that they were more likely to move past works quickly if they were felt to be difficult to relate to, 'often the more abstract images e.g. #23 *Poverty transmuted...*' (Lee, PU) (Exhibit 7, p. 158). Other works received comments such as, 'I just didn't get it', 'there weren't any words to explain it', 'I didn't take anything from it about pain', 'I needed text to put it in context' (Alex, NP). With abstract works, audience members placed particular emphasis on using the artists' accompanying text to aid their interpretations (the use of accompanying text to guide interpretation is discussed in the following findings chapter, sub-section 'Interpreting works'). Other audience participants 'rejected' works based on aesthetic values such as perceived level of skill or the art form (for example, 'watercolours that didn't grab me', Robin, PU-PRO).



Exhibit 8 *Struggles*

Struggles

Dawnique Savala

Acrylic painting
28" x 28"

I left this piece unfinished to speak of the struggles that I face with trying to learn to live with Rheumatoid Arthritis and with trying to continue making art. RA has affected my hands so holding a paintbrush has become difficult so I've started painting with my fingers. I've used this as a way to incorporate my experience with this disease into my work. My technique is not the only thing that I use. The shoes represent the idea that you can't tell what a person is going through unless you walk in their shoes. I may look healthy on the outside but if you were to look inside you would see the war that my immune system has waged against my body.

In accordance with Stewart (2016), who discusses the potential to harness metaphors in song lyrics, I found myself comparing *Struggles* and its message to a song by the band Depeche Mode called *Walking in My Shoes*. It was a song I had always related to because of the reference to pain but also the importance of not judging before having experienced the same things:

I would tell you about the things
They put me through
The pain I've been subjected to [...]
But before you come to any conclusions
Try walking in my shoes... (Gore, 1993)

For me, the artwork (and its accompanying text) heightened the strength of the song and its meaning as a way to explain how I have lived with pain, and others' responses to it. Additionally, it demonstrated how multiple formats of expression might be used in combination to provide an understanding of the experience of living with chronic pain.

Enjoyment of a work did not always equate to feeling that it was effective in its expression of the chronic pain experience, '[*Struggles*, Exhibit 8, p. 160] doesn't give me an insight into how the artist is feeling, even though I like the picture' (Alex, NP). This effect works in reverse too as *Transformation* (Exhibit 9, p. 162) is also commented upon by the same participant, Alex (NP), as raising a fascinating point about 'not being able to go back', even though the participant said that they did not like it as an artwork. The simplicity and accessibility of a depiction is appealing to some

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audience members. For example, *Hot Wax* (Exhibit 10, p. 163) is described by Robin (PU-PRO) as 'simple and effective imagery that captured me instantly'. However, this does not necessarily equate to an instant understanding of what was being expressed as the same person notes that they were 'curious to see what condition' was being depicted. Although someone with arthritis (which is the condition represented) may find they interpreted the work differently, if they were able to empathise with the imagery. Suggesting that the visual expression of pain may make sense to some people but even when relying upon accompanying text to guide understanding, the aesthetics may still be appreciated and engaging.



Exhibit 9 *Transformation*

Transformation

Joy

Watercolour
20" x 24"

Transformation as represented by the butterfly. There is no turning back to prior stages. The challenges of both physical and emotional pain has given me the opportunity - more like forced - me to grow and change. I am a much more compassionate, forgiving person than most people. Yet, I have learned how to be assertive, advocating and fighting for my rights as needed. I've also learned to set priorities - "to not sweat the small stuff" - because I don't have the energy or the time for stressing out over things and people that I cannot change. My priorities are for accomplishing life goals, bringing beauty, joy, and satisfaction.

Hot Wax

Sam Holtby

This represents the burning sensation of arthritic pain



Exhibit 10 *Hot Wax*

The symbolism of crosses in *My Body* (Exhibit 11, p. 164) raised a question of whether the artist feels the pain is crucifying, or whether it is society crucifying the creator Jackie (P) noted that the 'crosses being in three's stood out as religious symbolism'. Jackie goes on to ask if the crosses are a source of comfort in some respects, noting

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that the work left them with 'more questions than answers'. In this instance the text accompanying the piece does not relate directly to the imagery and is a broader piece of writing about the creators' experiences of life with chronic pain. As such it cannot be used to answer queries about the imagery in the piece. Instead the creation of the artwork may have been used as a stimulus to write the accompanying text. This process may be indicative of the interrelated nature of the multimodal expression of life with chronic pain achieved through creativity. It may also demonstrate that the expression of a pain experience is the most important aspect of creating a representation of pain, rather than attempting to clearly communicate a specific aspect of the sensation, for example.



Exhibit 11 *My Body*

My body

George Emma

Creativity always helps. We are creations – we create daily, every minute; some of us choose to see this and some not. It is all about the individuals' perspective.

People have no idea how it feels inside to live with pain, to be in pain non-stop.

I try hard to avoid showing people the truth of my condition because people do not like to see the pain and suffering. People will see me and judge me because of my appearance.

Living with chronic pain is a stigma and having depression is a way bigger one. So as a chronic pain patient I am limited inside my body and way too limited in society.

There are people who understand and people who pity me and people who use my disadvantage and jump the queue.

People who push me on the pavement and people who expect me to make space for them as I am not considered equal.

People who are just curious and people who may be interested in meeting you but when they see the cane or ankle support, they look away.

It is another disappointment because even medics behave the same way sometimes.

I know pain is very difficult to understand and to cure. Yet I am a human being living on earth, under the same sky breathing the same air. It is unfair to be discriminated against because of my condition and to be put on the side.

I do not blame anyone; it is just the way society is.

Chronic pain is a slow killer.

Temperature is indirectly referred to in regards to the expression of burning and heat of pain and the seeking of coolness or water to soothe. However, cold temperature is referred to in relation to the icy pains linked to peripheral neuropathy (Robin, PU-PRO), depicted in *Pain Without Words* (Exhibit 12, p. 166). Cam (P) states that pain has

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blocked their creativity and if they try to create 'it always seems to be flowers or birds. Perhaps sub consciously I am expressing rebirth and freedom'. Whether or not this expression of rebirth and freedom is the case, the symbolism linked to flowers and birds is interesting as it entails an implication that these would not be used in a work specifically expressing their chronic pain.



Exhibit 12 *Pain without words*

Pain without words

Deborah Ann

paper mache' clay, cardboard, glass, wire
and spray paint

14" (H) x 14" (W) x 12" (D)

I have peripheral neuropathy and find it impossible to describe having feet as dead and heavy as rocks while so sensitive that touch causes sharp pain, so I created this piece as a way of showing people what this is like. It also helps me put the pain outside of my body so it doesn't consume my mind.

Artistic style and personal taste contribute to the response regarding the creative appeal of a work. Jac (NP-PA) commented that *Sciatica* (Exhibit 13, p. 168) looks 'expressionist' in style, stating that this makes it appear somewhat 'outdated'. Robin (PU-PRO) noted that they were put off works that appear to be child-like in style, use forms that did not 'grab' them or had little explanation of the image. This suggests that a certain level of skill is required for engaging audience members but it may be that audience participants living with pain are less concerned with style and aesthetics when viewing the works, than these two participants (who do not have pain or pain status is unknown). Empathy and recognition of common themes and/or imagery may be sufficient to capture the attention of participants with pain, aiding a sense of connection with the work and creator. Additionally, it may be that the response to works varies according to context. If works were not included on a site which is presented as a form of exhibition, the responses may be different, in association with differing expectations of the creative pieces. This shows that the aesthetics, skill and style perceived to be in the works affect how effectively audiences engage with the pain expressed in the pieces. So, while a certain style in expressing pain creatively may be considered appropriate by a creator, it may be overlooked or rejected by audiences who do not engage with the style.

Sciatica
Martha Renault
Acrylic painting

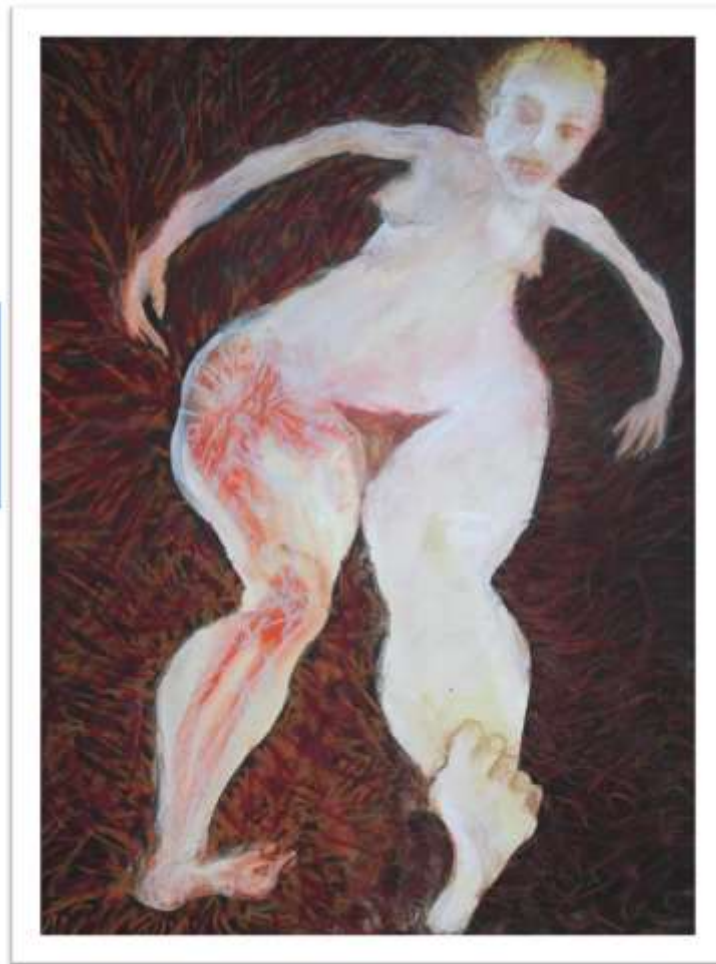


Exhibit 13 *Sciatica*

Audience for the works

On the consent forms, creators were asked whether they had a particular audience in mind when creating their works. Of the 23 creators who exhibited works, seven stated that they had created them for themselves while nine noted that they had no-one in mind. It is possible that these nine might have selected 'me' if this had been a closed multiple choice question rather than open-ended.

The pie chart in Figure 11 (below) presents the primary audiences noted by creators, for example, created for studies in art courses, for therapy, 'everyone', no audience in mind ('Not applicable'). However, some creators mentioned secondary audiences, most commonly family or others without pain, in order to try 'to explain to non-

sufferers what it is like' (Tatum, C). These comments were often linked to statements of not being understood or trying to explain their bad mood, suggesting a need for an additional or alternative form of expression than narrative. Five creators who stated that they did have a specific audience in mind noted groups external to their personal lives. Namely, Doctors, those not living with chronic pain, 'everyone', as degree course work, and as part of a course of therapy. There is an implication here that Doctors do not understand what it is like to live with pain. As their pain status is likely to be unknown to the patient this may not be accurate (this topic is discussed in the following findings chapter, sub-section 'Clinical encounters'). None of the creators who stated they had a specific audience in mind for their works went on to identify this as their friends and family. However, personal acquaintances did arise as secondary audiences for those who stated that they created the works for themselves. This suggests that there may be a difference in how having a 'specific audience in mind' is understood to relate to formal or informal sharing of works.

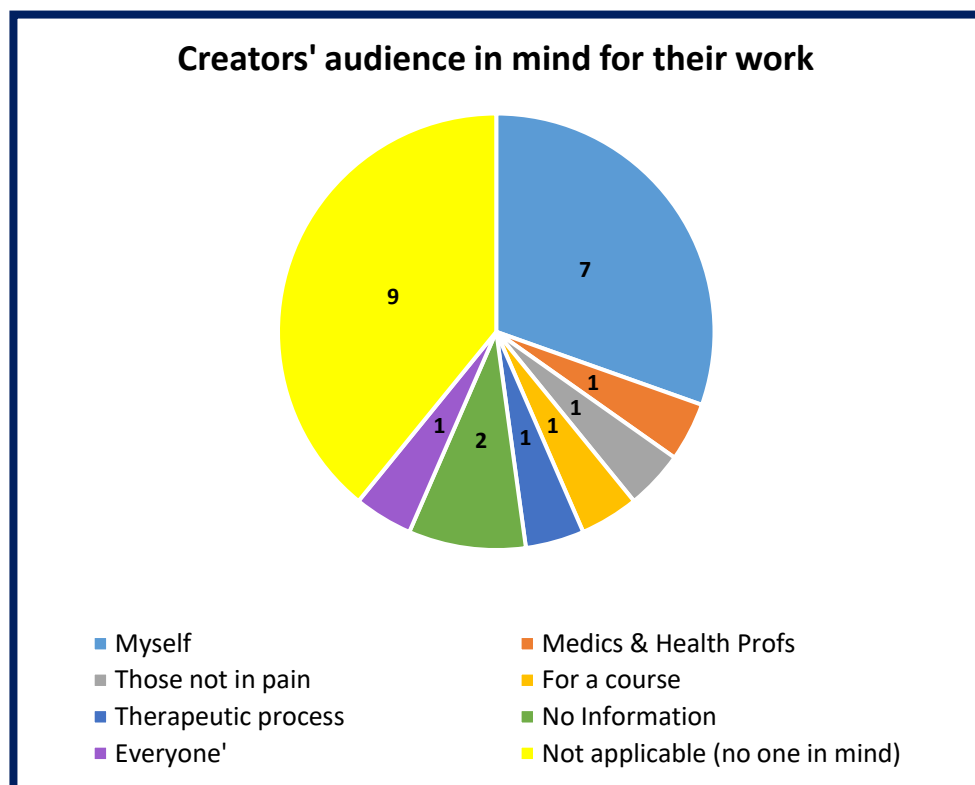


Figure 11 Creators' audience in mind for their work

There is also an element of inconsistency in relation to the answers regarding a specific audience and the additional information provided on the consent form questionnaire, or in the works' text label. For example, Dylan (C) noted that they had created the work to depict the nature and location of the condition but stated there had been no specific audience in mind. However, the stated need to be able to explain the condition visually implies a wish to communicate this *to* somebody. Another creator stated that the work was done for themselves but text elsewhere notes that the work was created because of the difficulty of describing the pain experience using words. This implies that it was made in order to for the pain experience to be shared and understood by others. These apparent contradictions may be explained by the conflict between the private experience of pain and public demonstration of it, together with the perceived need to keep pain private, which is discussed below.

Using creative works to talk about pain

A creator²⁷ notes of their experience in seeking a diagnosis that although they had physically drawn, with a finger, the area that caused them pain this was ignored on numerous occasions, although it is significant to diagnosis of the particular condition. The creator suggests that if someone had asked them to draw a picture of the pain's location, it may have made a difference to the length of time it took to obtain a diagnosis. It was noted that the work representing the condition enabled Chris (NP-PA) to make a 'reasonable estimation' of the type of pain/condition that was being represented.

Thinking about whether the creative works help people to talk about pain in general, Lou (P) wrote that the works make it easier as the ground work has been laid through 'non-verbal channels and this [...] opens the door to cover different angles.' Mel (P) notes that when sharing their art, they are able to convey their feelings surrounding

27 Unreferenced and no pseudonym given to lower likelihood of identification

pain, having felt scared and stuck previously. These thoughts were reiterated by Chris (NP-PA) who wrote:

I wonder whether it helps to break down barriers, enabling the audience to disassociate themselves a little – the topic is then about the art, the expression of pain [...] but is not as much of a personal statement of suffering

It is interesting that, Chris, a non-pained audience member, who also has no professional connection to pain, recognised that the distancing from the person to focus on the art itself was what might enable a ‘more collaborative engagement.’ These comments show the potential of creative works to facilitate a different form of communication about pain which connects to the idea of using an exhibition to share these and to provide insight into living with pain. The distancing from pain for the audience member is also of note. Allowing an object to represent the experience can enable the other person to engage with the pain in a way that feels safer emotionally and therefore more effective communication may be achieved. A creator, Frankie, argues for the visual communication of the experience of pain, stating:

The action of pain on your mind, your body, and your spirit cannot be described it can only be experienced. In seeing a creative work about pain, the viewer is given the chance to experience what we experience (Frankie, C)

August (NP) stated that Frieda Kahlo’s paintings have been used at talks they have attended about pain (by clinicians to medical students or other professionals), ‘to raise issues such as isolation from others’ and to show the whole life impact of the condition. August adds that in using the artworks, the intention appears to be ‘to get closer to patients’ experience and away from medical ‘objective facts’’. This implies both that patients’ experiences are distinct from ‘objective facts’ and that art enables patient voices to be heard. It might also be that the speaker incorporated images to increase engagement with the content. As such this may have aided a multimodal learning experience about life with pain for the audience members. Chris (NP-PA) agreed with this comment, adding that the group and works ‘permitted some discussion around the expression of pain’ and how this differs for individuals.

In response to my Facebook query about using the works to aid discussion about pain, Sam (C) commented that they do not talk about their pain: ‘the only time that it’s ever “talked about” is during a dr visit’ [sic]. This is contrary to de Montalk’s assumption that pain is shared with personal support networks when asking, ‘What of those who suffer alone – who have no family or friends with whom to share their anguish?’ (de Montalk, 2019: 125). Sam (C) is demonstrating that while they use creative techniques to express and represent their pain, it is still a private experience which is not discussed with their personal support network. This conflict is demonstrated in Hayden’s (C) discussion of the importance of considering the intention in creating a work.

Discussing the motivation for including physiological points of reference, Hayden (C) writes that the intention of the work is important. Creating for personal emotional expression or to convey a message to other people will affect the figurative elements depicted. Noting that the work can portray both emotions and convey a message to others, Hayden (C) adds that usually they have a clear point they wish to make. Hayden states that if it is something they want to share, they make a physiological reference point ‘so it will be understood better’. However, when creating for themselves, they focus more on psychological aspects and emotions they wish to release, ‘which doesn’t always have a physiological’ reference. This demonstrates not only that the works can be used in different ways but that the expression of pain in the works may be adapted according to audience and purpose. Intention in viewing may also be relevant to whether a physiological point of reference is required. However, Hayden’s comments also show that the works produced for ‘public’ consumption tend to include physiological points of reference as opposed to those created for themselves (the private works) which are more emotionally focussed. The implication being that they do not share the emotional and psychological impacts, of living with pain, with other people but they do use the creative works to describe physical aspects of the pain experience with others. It is this conflict between what is made public, or kept private, about living with pain, to which I turn next.

Public-private dualism

Linked to how pain is expressed, is the notion of whether or not to acknowledge it publicly at all. Bendelow (2000) writes that although pain is a personal experience, it is also a public concern and that cathartic relief may be gained through disclosure. Such 'cathartic relief' may be enhanced through the use of creative techniques to express the pain, due to their inherent cathartic benefits (Stuckey & Nobel, 2010). A conflict appears in the way in which pain is framed by participants as a personal and private experience, while also noted that others (by which is meant, those people who do not live with chronic pain) do not understand or see it because of its invisibility, or do not want to hear about it. Creators describe their works as being primarily for themselves, rather than for a particular audience, and state that the works are (generally) not shared with their personal networks. Contrary to this, comments are also made about creativity being used to express their pain because it is an inherent form of communication for these individuals, they have chosen to share the works publicly online (mostly with their own names), and they hope to raise awareness, while reducing isolation for those who also have pain. These apparent contradictions are emblematic of the conflict that exists for those living with chronic pain, regarding the public-private nature of the experience.

Based on the findings, I present here the concept of a public-private dualism in the experience and expression of chronic pain. The term 'dualism' is being used to highlight the simultaneous existence of two competing elements – the public side of chronic pain and the private experience. Chronic pain represents a multiple reality for the individual experiencing it when they attempt to hide from others its effects on them while being reminded of its presence through the pain sensations. The dualistic nature referred to here is most concerned with the conflict between wanting to seek understanding of the pain experience, but feeling that this is difficult to achieve because of the invisible nature of the condition and people's reluctance to listen. There is a desire to find support and others who understand, and to reduce isolation,

while feeling also that it is a personal and private concern. It is these conflicts I am referring to when using the concept of a public-private dualism in the context of chronic pain. However, I would argue that this dualism is in keeping with postmodern rejection of binary explanations, in favour of the acceptance of multiple realities and meanings. This public-private dualism is not a simple binary (either-or) but a balancing in the moment between private experience and public expression.

As an example of this apparent conflict, Kelsey (C) remarked that they have ‘learned to reserve [the creative works] for close friends and family’. This follows a statement that they had always represented pain creatively but had been ‘punished for it [as it] can be misconstrued by guilty parties as ‘dramatic’ and ‘political instigation’ [sic]. Although there are no further details about the content of other works by this creator (other than the one exhibited²⁸), and the attitudes of those viewing them, this remark demonstrates the potential difficulty regarding the reception of works. Negative responses have led this particular creator to reserve the works for those close to them. Consequently, a contradiction appears in the choice to share a work in this research exhibition. It may be the distance from the viewing of the works that enables creators to feel safe sharing their creative pieces in *Exhibiting Pain* (and on other websites). However, for those who joined the Facebook group, they were able to see responses and interpretations to the works. They were also able to interact with the viewing audience, which would suggest that emotional distance was less of an issue. Although the online method may in itself have provided a sense of security, as shown by Williams et al. (2012) who argue that the virtual environment can create lower levels of self-consciousness and greater candour.

A work shared by a member of the Facebook group (not part of the original exhibits) led to a comment about the ‘tremendous effort’ (Lou, P) involved in carrying on with daily routines and the difficulty for others to see how much is endured. Learning to ask

28 The work is not specified here to avoid identification of the individual concerned.

for help is mentioned as a coping mechanism by another participant. Although this is not explored by the participants, it is possible that for those who do not feel able to physically ask for help, the creation and sharing of works may be a means to seek and receive support. As most participants commented that their works are created for themselves or others in pain, and not generally shared with friends and family, this may be linked to the difficulty or reluctance in sharing their private experiences of pain with others.

The topics of privacy and of validation arose through discussion of artworks and the use of creativity. Phoenix (C) commented, 'mostly I kept my physical pain to myself. Even doctors denied I had it.' However, Phoenix adds that previously they had used art to express emotional pain but had been given the idea to represent the physical pain from someone who does likewise; suggesting that the pain is no longer kept private thanks to being expressed creatively. The use of past tense regarding the doctors' perception is unclear as to whether the creator now has received medical 'validation' of their pain, and, if so, whether the art played a role in changing this perception. Alternatively, it may be that Phoenix had reached a personal level of acceptance which meant that acknowledgement from doctors was no longer required. The change to communicating the physical pain suggests that prior to being given the idea of using art as a means of representing this, Phoenix had felt unable to express it but was now 'permitted' or able to do so through creative means. Sam (C) writes that expressing pain as an image 'helped me accept that this pain was valid and not simply "in my head"' [sic]. The statement implies a form of validation or recognition is gained through the expression of the pain in a creative work, helping to make it 'real', not only to others but to Sam personally. It is possible that this process, of art providing self-validation of pain, was Phoenix's experience also and accounts for the change regarding keeping pain to themselves and the denial of it by doctors. These points relate to comments about the self-doubt that people with pain can experience in response to the lack of medical 'proof' and others' (perceived) scepticism of their pain (Scarry, 1985; Gotlib, 2013).

Chapter Six: Creating and expressing pain

Some creators expressed gratitude at being part of the research, demonstrating a perceived value in sharing their work publicly. This implies both a need to be seen/heard and also a desire to show the work outside of their own network, even when it had been created for themselves alone. These points are illustrated by Phoenix (C) who wrote, 'I think it is important for people who suffer from pain to have a voice'. There is a recognition of the need for people with pain to have a 'voice' but also an implication that there is a wish to share the chronic pain experience publicly. Sam (C) comments that the pieces communicate to audience members with pain that they are not alone:

While I'm not comforted by others in pain, viewing the art strangely brings a level of comfort. It shows me that others "get it".

Pat (P) wrote of 'our community' in referring to people with pain and viewing the exhibition. Together, these comments demonstrate the importance of connection to others living with pain and the sense of gratitude that this can provoke. This is supported by de Montalk discussing the discovery of Daudet's *In the Land of Pain* (2002), stating that she was 'grateful for the shared experience, thankful for his sanctioning of my own pain' (de Montalk, 2019: 75).



Exhibit 14 *Buried Alive*

Buried Alive
Angela Talamantez

Collage on paper, ink
22" x 12"

The physical and mental cycle of pain after being buried under a roof collapse in a pool. The cycle of pain felt like it would never end.

Chapter Six: Creating and expressing pain

Variability of chronic pain is mentioned by Angel (P) who, in response to the work *Buried Alive* (Exhibit 14, p. 177), describes curling up in bed and acknowledging the severity of the pain. Angel (P) states that it is 'very hard to do that in the presence of other people.' Consequently, Angel is raising issues regarding the variability in pain levels, coping abilities and the visibility of pain to those people around, together with the fact that this can be difficult. The conflict in identity, and adapting to a changed body, is raised by a creator's response to *Disability 001-005* (Exhibit 15, p. 179), noting that 'there is a completely different person on the inside, not the person that you see' (Sam, C). These comments show the sense of the public performance of health being different to the private bodily experience of pain, as highlighted in the work *Do You See What I Feel* (Exhibit 3, p. 148) This is also demonstrated through Jackie's (P) response to *Struggles* (Exhibit 8, p. 160):

On the outside you have the socially acceptable face of getting on with it, to do as much as you can to meet the 'criteria' (whatever criteria that may be; medical, relationships, work etc) but the challenge you have to get to that point can be painful and difficult in so many ways.

Disability 001 – 005
Murder of Goths

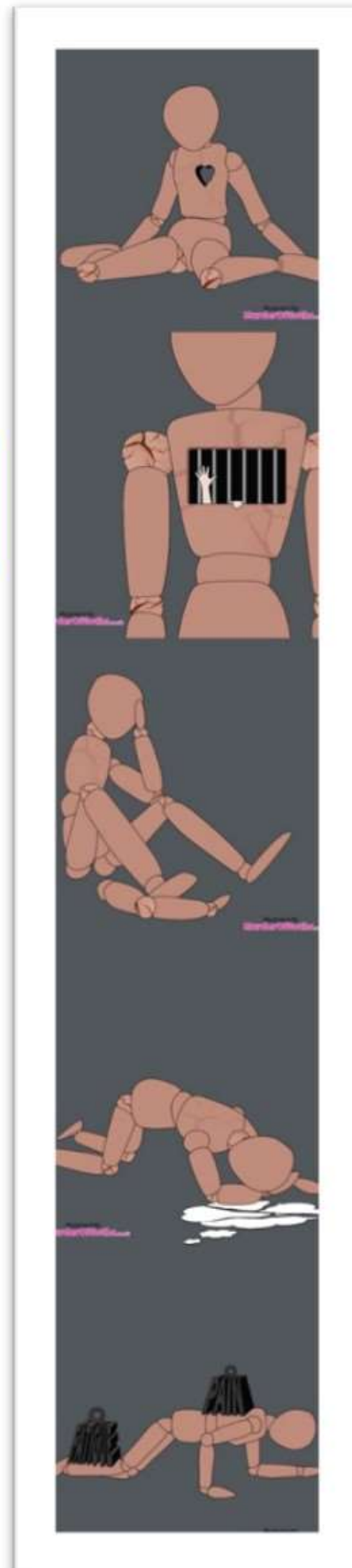


Exhibit 15 *Disability 001-005*

Chapter Six: Creating and expressing pain

The private nature of life with chronic pain is recognised by Charlie (NP-PA) who congratulates the creators for showing 'a very personal part of their lives.' Jo (P) notes that the exhibition was useful as they had not previously talked with other people about pain, except for medical professionals. While Pat (P) states that the exhibition does make them feel differently about chronic pain and they firmly believe that one of the strongest coping mechanisms for pain 'is the collective experience.' Consequently, the public acknowledgement of people experiencing persistent pain is important in order to achieve such a 'collective experience' and in enabling people to talk with others about their pain (apart from with health professionals). The use of an exhibition is effective in achieving this, as shown by Pat (P) who states that seeing 'this shared experience in a multidimensional format helps me to feel not alone in my suffering.'

Loneliness is picked up on by Phoenix (C) who notes their gratitude for the Facebook group and discussion, stating that 'otherwise it can be lonely.' Demonstrating again that the sharing of such works helps to reduce the isolation that can be experienced with chronic pain. Phoenix (C) adds that as years have passed, they have stopped telling doctors about their pain. Phoenix (C) keeps pushing in order to stay at home and be active,

but then I do not get the help I need. So, I'm starting to reach out for help and overlook the comments.

This quote demonstrates the complexity of living with the (in)visibility of chronic pain, given the need to be resilient against being accused of 'making it up' (Phoenix) while attempting to remain independent but supported.

I find it interesting that I have written 'independent *but* supported' rather than '*and*'. It suggests a personal response that to be independent usually entails *not* being supported, or vice-versa. In living with chronic pain, there is a need to retain independence *and* a need to feel supported, if only through the recognition of what you are experiencing day-to-day. However, it is the balancing of the two that appears to provide personal conflict for those living with long-term physical pain.

As the pain itself is not always shown or discussed, it is perhaps congruent that the same applies also to the creative works representing it. Sam (C) comments, 'I have never shown my family'. This raises the question of why these participants have chosen to share the works more widely, online, and if they have told family and friends of their doing so. Although one reason for not sharing with people close to them is presented by Angel (P) who writes,

what people see in my art is the thing I try to avoid – isolation and loneliness. I don't tell anyone really that these feelings make up a large part of scariness of pain.

Angel is demonstrating the difficulties of being candid to those close to them about living with chronic pain, and to those who do not experience pain. It is likely that in sharing works together with other creative expressions on the same topic, this was experienced as a 'safe' way to be heard and seen by people who understand, or by not being the only person articulating these experiences. Consequently, the process of connecting with others through the creative works and Facebook group has shown to be an effective form of support. This is demonstrated by the mention of self-doubt that arises with long-term pain and how it has been helped through viewing the *Exhibiting Pain* collection; Sam (C) writes:

I've wondered if I exaggerate my pain or if I'm too weak to handle it. So, in that way, this art is comforting...others get it!

Hayden (C) wrote that they had never expected to share their artworks (which were produced to express themselves with a therapist) as 'they were such a personal expression'. However, returning to university, Hayden used them in presentations. With time, Hayden (C) is now able to share all of their art, 'but at first it was very difficult to show that much rawness to others'. This may be the same for letting people 'see' how pain affects someone's life, through pain behaviours, body language and narrative. However, the use of creative techniques as an alternative format for doing so could provide a level of distance from self which helps the process. Other responses to the way in which people speak of their pain, and life with it, show the complexity of trying to understand the reconciliation of pain with the person's sense of self. The difficulty of working through this is demonstrated in the following passage, given at length to illustrate the conflict people experience in knowing how to talk about their pain:

I think it's personal. I used to say, "my pain". My mum noticed it one day and mentioned it. Now I don't know what I say!! In some ways - maybe this will sound odd? - I feel it is mine, and I need to embrace and accept it, in order to live as well as can be side by side with it. In another way, it's an experiencing I am having, and perhaps I don't want to 'own' it. I suppose of the list you give above, I am most drawn to 'live with pain' because yes I am in pain and yes I suffer with pain, but somehow somehow, me and Pain have to find a way to cohabit (Jude, P)

Denial of a change to body and self is touched upon by participants when responding to the works. For example, one writes, in relation to *Struggles* (Exhibit 8, p. 160), of their diagnosis of Rheumatoid Arthritis and the recommendation to wear flat footwear, that their heeled shoes 'spent years in the back of the wardrobe whilst I was in denial' (Raj, P-PA). This change to self and identity is noted by Harroff in the accompanying text for their work, *Wascally Wee Willy* (Exhibit 1, p. 144), in which they write that people retain a 'psychological profile of that fictional well person who existed in the past,' Harroff states that it is 'better and healthier to "embrace the mutant"'. The idea of mutancy or alien-ness is picked up on by Alex (NP) who notes on a VFF that they would ask a creator how they incorporate their pain into

the person they believe they are at their core. Is it alien to them or has it become part of their identity?

This quote from Alex raises a few interesting ideas. First that the pain may not exist as inherent to the person they are 'at their core' and that there is a division between the pain being 'alien' to them or it being part of their identity. In turn, this division may relate to how, and if, people chose to express their pain publicly.

The age of someone, and/or how long they have lived with pain, is raised by participants in the Facebook group, demonstrating a link to their identities. While this is something asked about on the consent forms (represented in Appendix i) it is interesting that participants raised it themselves in the Facebook group or on the VFF, whether or not they had completed a consent form²⁹. The following are a sample of phrases which were used by creators with reference to the duration of their pain: 'since 16 years [of age]', 'I'm 42 and have [had pain] since 2010', 'since the injury in 2007', 'I managed that for 15 years' and '6 months after the fusion'. These comments illustrate a concern with age and duration of pain, as well as the measuring of time since a procedure or the onset of pain. This may be due to experiences with needing to relate medical histories multiple times or because of a recognition of the change in self since the onset of chronic pain. Duration of pain, or age of onset, had no discernible influence on the need to create works expressing pain, or the nature of the representation itself. However, the duration that someone has had pain is shown to potentially influence the way in which they talk about it and, indeed, if they speak of it at all. For example, Sam (C) stated that 'after 20 years it's as much a part of me as the colour of my eyes.' This shows that the pain may become a part of the body and identity, which may account in part for why it is not discussed publicly, as it has become an inherent part of the person's sense-of-self.

29 It was stated on both sites, and the VFF, that consent was assumed to be provided by participating, or completing the form, but that it would be helpful for me to have completed consent forms.

Conclusion

This chapter has explored what creativity and being creative means to participants in *Exhibiting Pain*, together with the reasons why creators use such methods to express their chronic pain experiences. The forms in which pain is expressed creatively have been explored, such as through the use of language and aesthetic elements in the works. Discussion has explored which audiences, if any, participants had in mind when expressing their pain creatively and whether the works aid conversation about life with pain. Following this it has been shown that a conflict exists in how people with pain attempt to live with the invisible and subjective condition, while trying to obtain understanding and validation of their experiences. This is further complicated by a sense of other people not wishing to hear or witness their pain and it being a private and personal experience. Such conflict has been described here as a public-private dualism. The next findings chapter explores the broader experience of participating in the *Exhibiting Pain* project, viewing and sharing works in the galleries and the effectiveness of the exhibitions to increase understanding about chronic pain and empathy for those living with the condition.

Chapter Seven: Exhibiting and responding to pain

Introduction

This second findings chapter focuses upon audience responses to the exhibits and the interpretative process. Additionally, the chapter explores the experience of participating in *Exhibiting Pain*, either as a creator, someone with pain or someone without personal experience of long-term pain. Creators' experience of exhibiting works and audience members' viewing of works are discussed in relation to the data gathered. The enhanced expression, through the use of creative methods, can enable a richer understanding of the subjective experience, increasing empathy and helping to achieve validation of the chronic pain. The effectiveness of the galleries to increase awareness and understanding of life with chronic pain is explored, leading to a discussion of how empathy was elicited through the creative works. I begin by exploring the levels of participation which were achieved.

Participation in *Exhibiting Pain*

During the data collection period of the exhibition, 138 people clicked on the Visitor Feedback Form [VFF] page of the WordPress site. In total 17 VFFs were received, four with consent forms and the other 13 through the online WordPress form. The level of completion was therefore that 9% of the views of the form went on to be submitted. One of these has been excluded from the data as the responses received were not related to the creative works or galleries. On average six of the seven questions on the VFF were answered by respondents. The mean response rate for each question was lowest for question five, which 12 of the 16 respondents answered: 'Is there anything you would like to say to a creator, if you could?' Neither of the two health profession audience members answered this question, or the final question concerning the potential for such projects. The highest rates of response to VFF questions were concerned with the viewing of particular works, or the choice to move past any. It is

unknown however whether this is linked to them being the first questions on the form, or to the nature of the questions.

In total there were 1395 individual visitors to the WordPress site over the data collection period. Visitors to the WordPress site originated from 52 countries, the largest five categories of these are presented in Figure 14 (Appendix i), showing that the largest proportion of visitors originated from the UK and USA. This is unsurprising given my location in the UK as the researcher, and that 61% of the creators reside in the USA (30% reside in the UK) (see Appendix i for demographic features of participants).

The total number of visitors to the WordPress site was measured during the period of data collection, when all of the final 23 works were featured (13th June 2016 – 9th October 2016). On average each visitor viewed/visited the site five times. The WordPress site recorded the method used to reach the site, for example, being directed to it by clicking on a link in an email or via Twitter. These details, together with the number of visitors per category, are shown in Figure 16, Appendix i. Referrers included University email addresses and other email accounts (for example, through the JISC academic mailing lists), Facebook and Twitter promotions, The Open University promotion, Critical Physiotherapy network, search engines, London Arts Health electronic Newsletter and 'other'. Referrer details therefore exist for 1247 of the 1395 visitors (89%) to the site over the data collection period (once all 23 works were uploaded). The remaining 148 visitors who are unaccounted for may have entered the website address into the browser directly.

Having followed a pragmatic approach to managing the Facebook group, a statement in the group rules noted that participation in the group meant that consent was assumed to have been given. Although there was strong encouragement for group members to complete consent forms and I explained the value of these to me. The lack of completed consent forms from the majority of Facebook members meant that it

was difficult to glean comprehensive or reliable demographic information about these participants as a whole. Information available about the group members is presented in Appendix i. However, overall the group consisted of 92 members at the end of the data collection period, of whom 31 were classed as 'active' participants. The other members did not comment or interact with content (Figure 15, Appendix i). Of the Facebook members, 25 were recorded as living with chronic pain and 52 as 'pain unknown (PU)' (please see Table 2 in Appendix i). There were an additional five Facebook members with chronic pain who are personal acquaintances of mine. Without demographic information being provided by some participants on consent forms, it is not possible to state their gender, age, nationality or profession. This information may have been inferred from some participatory comments, or through information that was publicly available on their Facebook profiles. However, I did not feel it was in keeping with the ethos of respecting what participants wished to divulge, to the researcher and group, to actively attempt to discern such details from their personal social network profiles. Those audience members who did complete consent forms (as opposed to those visiting the WordPress site as detailed above) were recruited primarily through academic mailing lists, followed by Facebook promotion, as shown in Figure 21, Appendix i. This information is taken from those who completed consent forms (which, unlike the VFFs, included this question for data gathering purposes) which may explain why there is a particular spike for the academic email response, given that this demographic are more likely to understand the need to complete a consent form for research purposes, and therefore more inclined to do so, unlike other audience members. It should therefore be considered alongside other data, such as the figures for new Facebook members following this promotional technique, as shown in the line graph in Figure 22 (Appendix i).

A large increase in membership of the Facebook group occurred following the academic email promotions. This is shown in Figure 22 (Appendix i) which presents the rate of visitor numbers to the WordPress site and new Facebook group members over the initial periods of establishing the exhibitions. While total visitor numbers, and other details I have referred to, relate to the period from 13th June 2016 onwards,

when all of the final 23 works were included, I have included a slightly different selection of weeks here to demonstrate the spikes in numbers before and after certain activities, detailed below.

The figures for week 9-15th May 2016 are included as it was on the 13th May that I notified creators that the galleries were now live, though some works were continuing to be added to the sites. This led to an increase in visitors to both sites. Again, on 13th June I promoted the sites and project to the academic JISC mailing lists which created a spike in numbers that week for both sites. The inclusion of the weeks following these spikes is intended to contextualise the data by demonstrating the extent to which this level of activity was unusual.

Pain status of audience

As consent forms were not compulsory in order to join the *Exhibiting Pain* Facebook group, or to participate in the research (except for creators), the pain status is not known of all audience members. Sometimes this could be inferred from content on the VFF or in Facebook comments, as discussed above. While not limiting participation in this way, the absence of the completed details on a consent form means that it is difficult to fully assess the extent to which audiences consisted of different demographics, such as those with or without pain or if working in allied health professions. However, of those who completed the VFF, and participated in the Facebook group, the pain statuses were recorded as shown in Table 2, Appendix i (I have differentiated those who are personal acquaintances of mine in order to provide transparency):

Kim (P-PA) responded to the demographic survey question about whether or not they have pain, stating: 'Yes, back pain, but very mild in comparison to the exhibitors'. This response may be motivated by acquiescence and following social norms to downplay personal pain experience and not take away from those exhibiting their works. It may also be that the works led the audience member to acknowledge and recognise others'

pain above their own. In this sense the person is overlooking the subjective and relative nature of pain, to give greater validation to the pain experience of others' or a wish to downplay their own experiences.

Being acquainted with this person socially makes it difficult to switch off personal opinions of why they made this statement, especially given my knowledge of their experiences with pain. This leads me to wonder if such a method (utilising personal acquaintances as participants) provides additional insight into the acquiescence that research provokes. Or whether such acquiescence was heightened because the person knows me, the researcher.

Exhibition experience

Audience experience

Audiences were asked about expectations of the works or what would be featured in the *Exhibiting Pain* galleries. Some audience members expressed surprise at the content, 'some of the images were more positive than I had expected' (Kim, P-PA). Whether this is based on Kim's personal experience of pain is unclear. If Kim struggles to live well with pain this may have evoked the surprise at the positivity featured in some works. Chris (NP-PA) wrote a thoughtful piece concerning what they expected to encounter in the works:

I was expecting to find a broad range of art but anticipated that all of the pieces shown would be focused specifically on the symptoms; vivid and aggressive (for want of a better word) expressions of pain, with sharp imagery, bold colours and very frustrated media. While these are certainly present what I have been surprised at is how elegant and subtle some of the subjects are.

An appropriate inference from these comments is that visitors expected a focus upon the adverse sensory experiences of pain, together perhaps with the negative impacts of this on someone's life. However, the creators challenged such expectations through their focus on themselves as people and their interests, rather than strictly focussing their works on the experiences of living with pain. This suggests that the creators (arguably, this may be generalised to others living with chronic pain) do not necessarily distinguish between themselves, their interests and their life with pain (they are intrinsically linked after-all, as illustrated by Sam's (C) comment quoted earlier about pain being as much a part of them, after 20 years, as the colour of their eyes). However, audience members were perhaps inclined to see the individual with pain as separate or different from the *person*. While there is a need to express the pain experience there is also a wish to present the creator's identity beyond the condition. If the exhibition had been described differently it may be that this was less surprising to visitors. For example, presenting the exhibition as being about 'people with pain and their lives', rather than the 'experience of life with pain.'

Other comments about which works stood out were linked to the viewer's response to the work aesthetically or in terms of the perceived level of skill. For example, comments included 'visually pleasing' (about *Transformation*, Exhibit 9, p. 162) and 'interesting piece' (*Hey Doc, Have You Figured It Out Yet?* Exhibit 16, p. 191) (both Kim, P-PA), 'I loved the quilt aesthetically' (Alex, NP, about *Phoenix*, Exhibit 5, p. 152). Some comments engaged with the meaning of the works through the combination of the accompanying text, together with the aesthetics, and the multi-modal format of these appeared to be what caught their attention. For example, Billie (NP) wrote of *Transformation* (Exhibit 9, p. 162):

I loved the butterfly, its uplifting and the philosophy behind it is quite remarkable from someone suffering long term pain

However, the response of a participant with pain was somewhat different. Pat (P) noted that the same work was one they moved past quickly because of being wary of a "'pain makes me a better person" narrative', linking this to personal experiences of life with chronic pain. Three people added comments relating to the individual and

subjective nature of the persistent pain experience, which was inferred to be their reason for taking time over each work. All three of these participants experience pain themselves and it may be this that increased their awareness of the individual experience of the condition but also their interest 'in how other people in my situation express themselves' (Bryce, P), together with feeling that 'it's a privilege to view such personal insights into chronic pain' (Jackie, P).

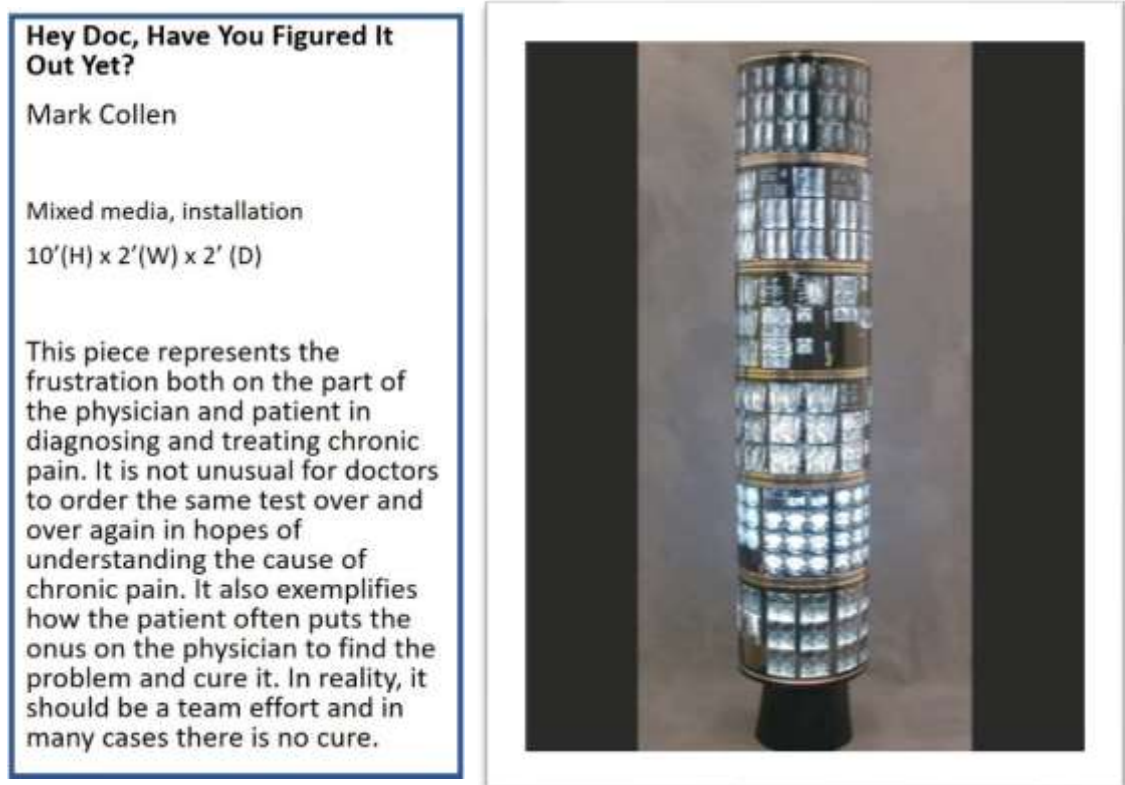


Exhibit 16 *Hey Doc, Have You Figured It Out Yet?*

Reasons for moving past particular works included a dislike of content where this provoked negative emotions, such as making the viewer feel uncomfortable. An inability to relate to or understand a work was the most common explanation for wishing to move on to the next piece, 'often the more abstract images' (Lee, PU), being representative of these comments. Dislikes of style, such as Robin's (PU-PRO) comment featured above about disliking watercolours (though it was not made in reference to a specific work), or the quantity of accompanying text, 'no titles or little explanation' (Robin, PU-PRO) as well as 'those with too much descriptive text' (Rowan,

Chapter Seven: Exhibiting and responding to pain

NP), were also factors in audience engagement with the works. The ability to relate to works influenced how Lee (PU) engaged with them, choosing to move over works which they found more difficult to relate to or visually unappealing. Bernie (PU) noted the following process of engaging with *Out of the Box* (Exhibit 17, p. 192):

I left the box. It made me uncomfortable because it is so raw and emotional. But I came back to it. So I was able to engage, but had to do so in stages as I found it quite personally confronting,

Bernie demonstrates awareness that the work engaged them and a wish to re-visit it but a need to take breaks.



Exhibit 17 *Out of the Box*

Out of the box

Kiris Ralph

Mixed Media

I think it's a box,
Yes, I'm inside the box.
Can you hear me? Can you see me?
I would call to you if I could,
But I don't have a voice, I don't have the words,
That would tell you where I am, that would tell you
how I feel,
That would ask you to help me.
I'm inside the box, I'm inside the box, I'm inside the
box,
Can you see me?
The creature inside tries to hide me, Tries to ride
me, tries to guide me.
For a long time I stood still, Had no free will,
As it dragged me like its kill.
And then, like a dazzling sunrise, I was filled with
hope,
At first I had to drag my aching body,
And take tears with every step,
But hope grew and grew,
And each day a little of me began to shine,
To feel my strength, my resilience.
Stronger I grew and stronger I am.
I still live everyday with this creature,
And it tries all its tricks and its fear,
Some days will be harder than others,
But I get to the end of the day,
And I recall when I wasn't here,
And I look for the hope in tomorrow,
And lock that foul creature away...IN THE BOX.

Sam (C) commented that viewing the works is not distressing, stating that the works demonstrate that other people understand, which brings a level of comfort. This suggests that the therapeutic benefits of creation do not apply solely to the creator of the individual works themselves but that the viewing of works has a supportive,

therapeutic, role. It is not only the visual representations themselves which prove helpful for audience members, as demonstrated by Bryce (P) who noted that the text was very powerful, 'therapeutic and motivating.'

Creators' experience of exhibiting

A question posed by Jackie (P) highlighted some important points about the participation of creators in the project. Jackie asked whether contributing to the exhibitions was a positive experience for creators and if their views had been affected as a consequence of receiving feedback and participating. This question demonstrates that it is important for creators to have gained something positive from participating in the exhibition. However, audience members may perceive that the positive experience needs to be more than the actual act of sharing their works and experience. This may relate to a concern regarding the possible exploitation of creators and/or be a result of not understanding the positive impact that sharing their works has in enabling an individual to gain validation of their pain experience. Jackie (P) developed their query about the creators' experience further:

Whilst it might help the viewers of the exhibition to understand chronic pain in new ways, if the artists didn't feel it was beneficial to them, should the use of creativity be suggested as a possible way of communicating pain during consultations etc? What are the ethical issues?

This demonstrates the concern that creators may find the process of sharing their works difficult or distressing and that this could have broader ethical implications if applied to clinical settings. As Jackie has chronic pain it is possible that this concern may be related to personal experiences. While I did not pose these questions to creators directly, they were used to inform questions in the Facebook group, for example when I asked if people had found the works useful in helping them to talk about pain.

Some creators produced their works through projects for arts courses which therefore entailed a specific motivation, aim and target audience for the work. Having shared the

creative pieces with teachers and peers, the prospect of sharing them in this research exhibition is likely to have been less intimidating than it might otherwise. In addition, it may be felt that these particular works were produced in order to be exhibited and shown. Again, this might affect motivation in sharing their works in *Exhibiting Pain* and the expectations they had regarding responses. It may also have influenced which works they showed; for example, Hayden (C) notes that there are pieces which they have not shared with anyone, despite having grown accustomed to sharing works in university presentations.

Data gathered in the course of this research has explored creators' responses to having their work interpreted, and the experiences of the Facebook group, but not to the specifics of participating in the online exhibitions as a whole. However, 16 of the creators (70%) were recruited through the PAIN Exhibit website where they were already exhibiting works (its former Director, Mark Collen, also has a work featured in *Exhibiting Pain* and is included in this number). A number of creators also have their own websites, featuring a range of their creative works. Consequently, many were familiar with the experience of sharing works publicly through online methods, although not with the exhibition being part of a research project and many had not received interpretations of their works before. Those who chose to join the Facebook group were therefore able to engage with this aspect of the research project and had the opportunity to respond to interpretations and discussions about their works.

Exhibition impact

Of the 17 participants who completed some or all of the VFF (none of whom were creators, although there was nothing to prevent them from doing so had they wished), 10 noted that the exhibition had altered their view of life with persistent pain in some way. It might be expected that those people who do not live with pain were the most likely to have their perceptions about life with pain influenced by viewing the creative works. However, of the audience members who completed the VFF, six of the eight (71%) with chronic pain said that their views about the condition were changed,

compared to half of the audience without pain. This may arise from being able to explore others' representations of their pain, allowing them to see beyond their own subjective experiences.

The representation of the subjective nature of the condition, and the importance of this, was remarked upon by both those people who felt that the exhibition made them think differently about life with pain, as well as by those who felt no difference had been made. For example, Lee (PU) remarked,

...it helps you see things from a different perspective and really highlights the aspects of their condition that are most pertinent [to individuals living with chronic pain]

Pained audience members expressed surprise 'at how interested I've been and how helpful it has been also' (Jude, P). This is an interesting remark as it shows that surprise at the value and interest in the works was experienced by both audiences with and without pain. Jude (P) proceeded to state that they have been able 'to ponder the pain 'from all angles' and reading other people's insight has been invaluable'. It is worth highlighting that the works have helped to provide alternative viewpoints on living with pain for those audience members who also experience it but who may not have been anticipating this response to viewing the works.

Three people noted that a change had occurred in how they were thinking about visually or metaphorically representing pain, as opposed to changing their understandings about living with pain itself. For some the works reinforced or developed knowledge or beliefs already held. This is illustrated by Charlie (NP-PA) who commented, 'I was always aware but I think many of the images captured the emotions of suffering pain', demonstrating the effectiveness of the exhibition to communicate aspects of what it is like to live with the condition. Although whether it communicates so effectively to those with no connection to chronic pain is unclear. This suggests that it is possible to share the experience of living with pain in this format, allowing the condition to be understood and empathised with. Also, potential

benefits from viewing works include encouraging people to explore this form of expression of chronic pain themselves.

Park-Fuller, writing of staged autobiographical personal narratives (2000, cited in Sinding et al., 2008), is cited as suggesting that audiences ‘take the risk of witnessing artistic testimony’. In keeping with Daudet’s statement that one must think of someone on the receiving end of witnessing pain (2002), it is noted by Park-Fuller (cited in Sinding et al., 2008) that performers must attempt to consider the audience’s needs, concerns and expectations. This may be one reason that creators state they do not commonly share their works with their own social network. While it makes creators’ choice to share works online seemingly more surprising, it is perhaps due to the lack of personal ties to those viewing that enables them to do so. Although Sinding et al. (2008) argue that art can lend boundaries to what is difficult to witness and endure in everyday life, which may make the witnessing of pain more bearable through creative methods. It is the generation and elicitation of empathy and validation of the chronic pain experience that seems to be of great benefit to audience members and creators in the sharing and viewing of creative works representing pain. This is picked up on next in relation to the viewing and interpreting of works.

Viewing

Viewing works about people’s pain was described by a personal acquaintance (who does not live with pain) as ‘depressing’ (2016, personal communication). I raised this with the Facebook group to obtain a response of whether it was a sentiment that was shared, understood, or rejected by the audience members. Riley (NP-PA) responded that the gallery can be depressing ‘but it can also be illuminating’ in increasing understanding about life with pain. Another response was from Angel (P) who was curious if the person concerned had experienced chronic pain. By implication this comment suggests that the experience of persistent pain may influence the response to viewing the works. Angel (P) goes on to raise interesting questions about the viewing and interpreting of works, stating that they ‘find it hard to see any type of art as depressing’, adding:

If this person saw the pictures without knowing what they were about, would they find them depressing, or is it an unconscious reaction of wanting to ignore real issues that are confronting for people?

This shows that while the subject matter may not be upbeat in content or nature, the value of viewing the works is perceived to be different or greater than the aesthetics of the pieces. It also demonstrates a belief that people would not wish to be confronted with difficult or upsetting issues. It was therefore of interest to understand what motivations people did have in viewing the creative works.

The motivation for viewing and, where appropriate, sharing works in the Facebook group was queried using a 'Poll' option. Response options were set so that participants could add their own answer options too, if they wished. Two options were added by participants:

- 'Hopes that the more our work is shared, the better that Drs and researchers will understand pain'
- 'To share own artwork as means of communicating suffering which can't be expressed by words'

The latter was an expansion upon one option I had provided: 'To share own artwork, poetry, etc.'. It received more votes which suggested that the additional detail in the option, about the motivating factor in sharing the works, was of particular importance to participants. However, it may be that once it was added to the poll options, and selected more than once, it appeared higher in the list than the original item, gaining it more attention.

Figure 12 (below) presents the voting values from the poll. As part of the process of having personal acquaintances as participants I discovered that their decision to view works and contribute to the project was not simply to support my doctoral studies but to learn more about how best to support me (and other acquaintances), as someone with chronic pain (Main, 2018a). While this is inherent to the category of wanting to 'learn more about life with chronic pain,' it provides an additional component to that

motivation for some visitors (in terms of being able to use that knowledge to better support acquaintances who live with the condition), which I may not have considered without my personal acquaintances being involved as participants.

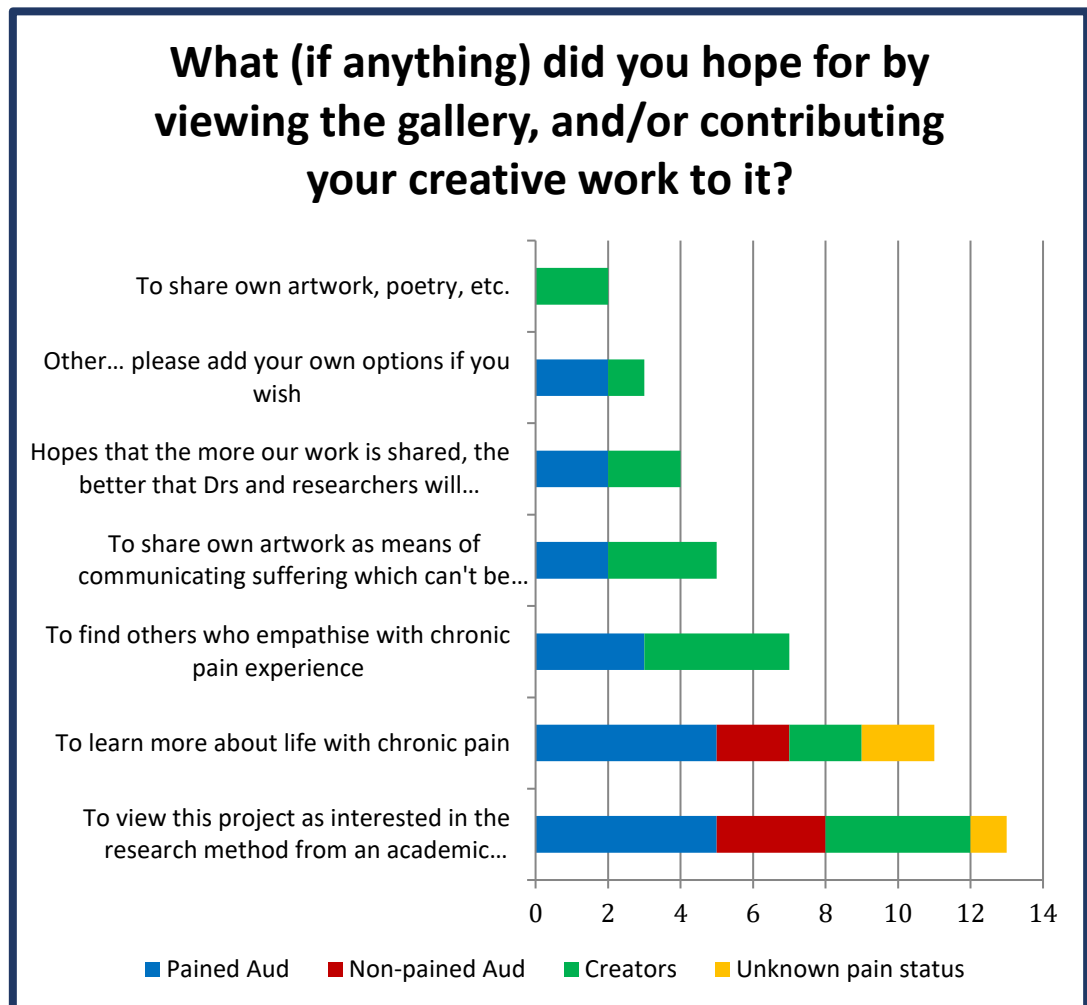


Figure 12 Motivation for viewing and sharing works in *Exhibiting Pain* Facebook group, by audience pain type

One reason for using a poll to ask the question was in the hope of engaging participants who may be reluctant to post comments in the group, as the poll provided an easy and quick way to participate. Having had a surge in membership following a recruitment drive using academic email lists (see Audience recruitment, in Chapter Three: Method and methodology), I was interested to know if my inference that many people had joined out of curiosity regarding the research method was accurate. The

result for the 'academic research' voting option was the largest, however this still failed to engage more than one person who had not otherwise participated in the group in some way. This suggests that while the members of the group were viewing it from a range of perspectives, those actively interacting were more than merely curious about the method. The post was 'seen by' 49 of the 95 members (47%) and 21 of these participated in the poll (engaging 22% of the total members, and 43% of those who viewed the post). This was a greater response than obtained on postings involving questions and on images, which generally only engaged a handful of people at most, and suggest that poll options are an effective and straightforward way to engage participants in a Facebook group. Figure 12 (above) presents the poll responses, broken down by audience types for each voting option (those with or without pain, creators, unknown pain status).

The VFF did not include a question concerning the motivations for viewing the exhibition and no respondents added remarks on this matter. Therefore, their direct motivations are unknown. However, other comments made on the forms relate to this topic. For example, comments were made regarding an interest in the method of data analysis of the project and an interest in understanding the pain of a family member, as well as finding support through viewing the works. Bryce (P) wrote that they were 'interested in how other people in my situation express themselves.' Jude (P) noted that viewing the works, and discussion in the group, had helped them to process a diagnosis and think about pain from multiple perspectives, describing reading others' insights as 'invaluable'. This may have been part of their motivation in viewing works or it may have been an unexpected benefit.

On a similar note, a relation remarked to me that viewing a particular work had enabled them to recognise their own condition. While they were already aware of it, they had been in a state of 'denial' about the condition until viewing the piece. For me, this was a surprise and helped to remind me of the value of the research and viewing such works. This was a helpful motivating factor and brought the realities of the research to me in a new, personal, manner. It also highlights the way in which such works may help with understanding diagnoses.

In viewing *Do You See What I Feel* (Exhibit 3, p. 148), Alex (NP) noted that they did not gain insight into what fibromyalgia feels like, which they had hoped to. This is representative of what may relate to the expectations of what the works would feature, and what may be gained from them. Rather than engaging with the message the creator wished to communicate, the audience member tried to construct an interpretation about life with the condition from the visual depiction and colours, as opposed to thinking about the psychosocial experience of living with pain. This suggests that a focus on the audience agenda in viewing may lead to the creator's own 'message' being overlooked. Perhaps meaning that the message someone with pain wishes to express may not be communicated effectively, depending on the agenda of the viewer. However, if the creators are not concerned with 'correct' interpretations this might not be a significant concern.

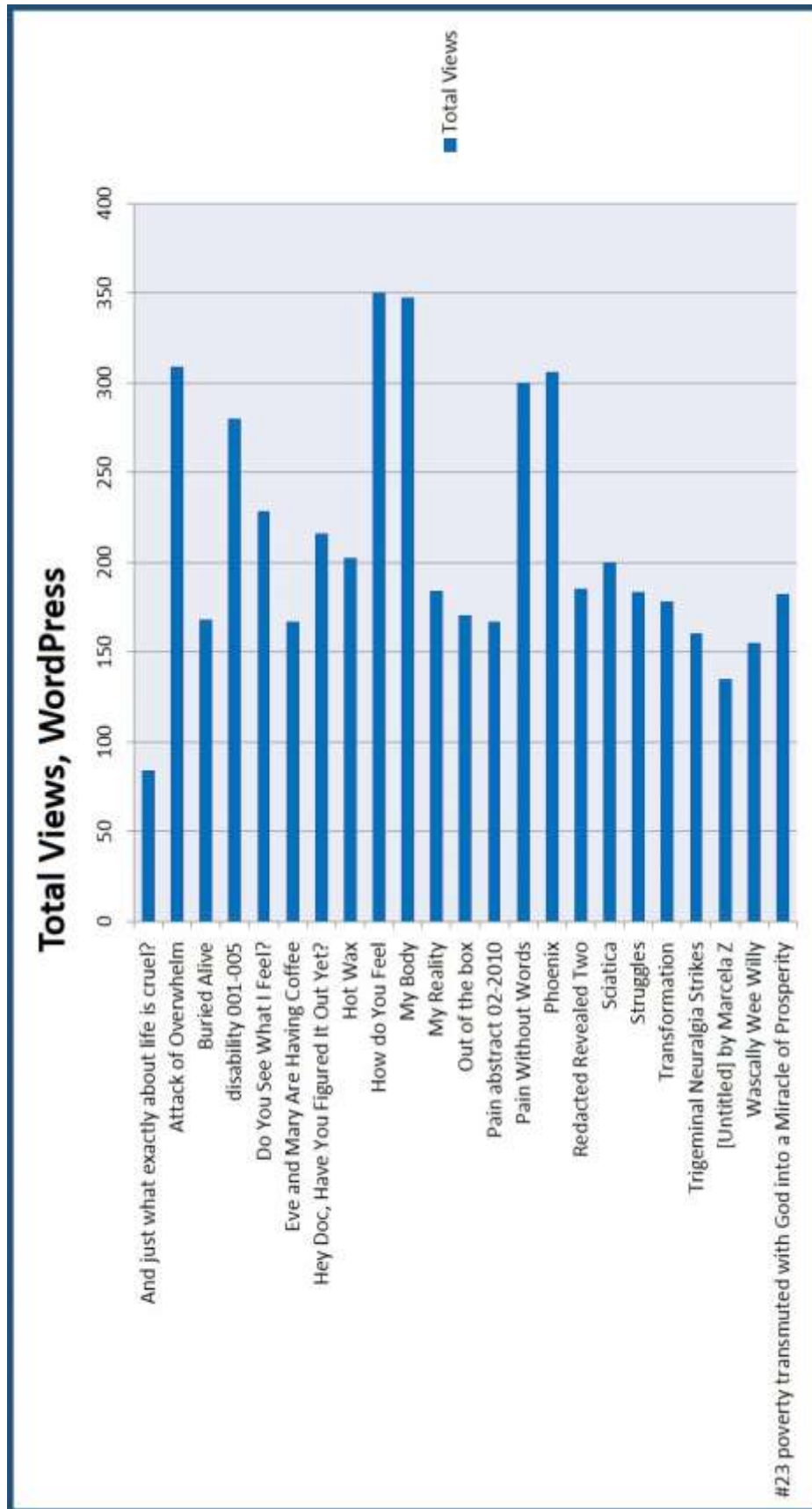


Figure 13 Total views of each exhibit on WordPress, during the data collection period

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The viewing figures for each exhibit (on WordPress, over the data collection period) are presented in Figure 13 (above). It was not possible to know, from the statistics provided by WordPress, if visitors returned to particular works. However, it is likely that the works with lower visitor numbers are due to a lack of returning visitors. The most noticeable example of this is that the stream of consciousness piece of writing (*And just what exactly about life is cruel?*, Exhibit 20, p. 213) received a lower number of visits, which might be due to a reluctance to engage with a piece of text as opposed to all the other works which were visual. Although *Attack of Overwhelm* (Exhibit 18, p. 203) was the third most visited work on the WordPress site it did not elicit any noticeable discussion or comments in the Facebook group. It is possible that the visual depiction in the work is striking and self-explanatory, without generating any particular points of discussion or debate. Such viewing figures demonstrate that the style of work is important in achieving views and engagement but that a lack of discussion on the work did not necessarily correlate with a dislike or lack of empathic response to it.



Exhibit 18 *Attack of Overwhelm*

Interpreting works

Chris (NP-PA) discusses the topic of interpreting a work and the sense of responsibility involved in this, stating that there is a 'social driver' in not wanting to misinterpret something that is so important to the artist. In discussing such concerns, Chris notes that this is most likely to be an issue 'where the art was being used as a diagnostic tool', showing again that the motivation in sharing and viewing the work may influence not only the interpretation but its implications. The risks of misinterpretation were further demonstrated through one work which raised discussions in the Facebook group about whether the level of skill or technique used in works would have a bearing on the perception of pain experienced. Kim (P-PA) writes on this topic that just a 'little bit of red and only this big [may be interpreted as] therefore it can't hurt that much'. Where some works were described by audience members as being 'childish' or crude in execution, this was linked to a certain dismissing of the pain experienced alongside. This occurs with children who may not have learnt the appropriate words, pain behaviours and body language in order to communicate their pain effectively, leading to their pain often being dismissed or underestimated (Carter & Simons, 2014). A creator picked up on this by noting that in their artwork they felt they had depicted their level of pain through the application of certain stylistic techniques³⁰, however the format of the work led to interpretations describing it as childlike and the pain being underestimated. Consequently, the perceived skill level and stylistic approach is shown to influence the interpretations of works and assessment of pain experienced by the creator.

Discussion of interpretation of the works, as opposed to more general responses to viewing, took place in the Facebook group. This arose through me asking if the works need to be interpreted. Participants commented that they did not think that interpretations were necessary if the viewer feels something in response to the work.

³⁰ This is kept vague to reduce identification of the work and creator

This links to a comment on another Facebook question where Sam (C) states their belief that if you feel nothing when viewing an artwork, the artist is unlikely to have accomplished what they intended, especially in the case of representing pain. One creator, Leslie, commented that they do not like when their work (or that of others) is interpreted as they are usually misunderstood. This is likely to be linked, at least in part, to the motivations in creating their works and sharing them. Leslie (C) adds that the emotional and nonverbal responses are the most important thing. The same creator responded to my own thoughts, which I shared, about whether an emotional response is a form of interpretation; that is to say, if a response of any sort is to be understood as someone interpreting the work. Leslie (C) responded stating a belief that interpretation is a cognitive and conscious process (also stating that this makes it subjective and ‘therefore fabricated’) but responses are ‘more authentic, something unconscious’. Kelsey (C) agreed with these comments, adding that ‘interpretation is mostly projection’. This raises the question of whether empathic responses are occurring because the works are being interpreted on a cognitive level or through an emotional response. Indeed, a larger question is whether the two could, or should, be separated.

Research participants are more concerned that the reporting of findings should not represent them unfairly, write Sinding et al. (2008), rather than being most concerned with the possible misrepresentation of the findings. It is possible that the same applies to the interpretation of creative works. Creators demonstrate a lack of overt concern for the works being interpreted ‘correctly,’ but they may be more concerned about the fairness or favourableness of the interpretation. Audience members without pain felt a sense of responsibility to interpret a work as the creator would wish. Also, when considering a work about chronic pain, a motivational factor in looking at the piece is to understand the artist’s intentions and meaning, in order to respond empathically and appropriately. This links to a broader finding in the data about audiences and interpreting the works ‘correctly.’ Those audience members who do not have pain were most concerned with reading the accompanying text to guide their interpretations and find out more about the artist’s experience and motivations.

Audience members with pain (whether they are active in creative pursuits or not) were not concerned that their interpretations should accord with the creators' intended meaning. Instead, this group was happy to find works and text they could empathise with and share with others, to aid the communication of their own chronic pain experience. Creators were akin to pained audience members in their interpretative responses to the works. While they less frequently mentioned a reduction in isolation, they did note it as a motivating factor in sharing their works (to help others with pain). They also mentioned finding others who express pain the same way and broadening their own means to express pain by using the other creators' works in the gallery to do so. Although creators often stated that they do not share their works or talk about their pain, they did note that the works helped them to explain their experience to people. This suggests a desire to have their pain recognised and perhaps helping to motivate them to find alternative, new, ways to achieve this. Or, while not consciously seeking a way to communicate, finding the works enabled them to do so.

Noting that the fabric and blue used in *Pain Management* (Figure 10, p. 154) looked too sweet and soft, Stevie (P) noted, 'I see nothing soft in my own experience of pain' and is consequently perhaps rejecting the concept of living well with pain. While Billie (NP) was drawn to the positive message of metamorphosis featured in *Transformation* (Exhibit 9, p. 162), Pat (P) rejected it on the basis that they are 'leery of the "pain makes me a better person" narrative'. Together, these responses show that positive imagery may evoke strong responses by those with pain. This may be akin to the rejection of the *Pain Management* piece as 'too soft' for chronic pain. Jude (P) writes that they feel it is dangerous to tell someone to be positive but that it is inspiring to hear others' stories of finding positivity. This implies that being told what to do or feel is not helpful but that someone may find help or inspiration in others' experiences, as they engage with those works which they feel able to relate to. Perhaps while attempting to manage their own pain, positive works feel more isolating than inspiring or relatable for some audience members. There is a need or desire to see works which present the difficulties of living with pain rather than perceived positive messages that

may exist alongside the condition, or arise out of it. As Sam (C) remarks, the level and type of pain, and how it is presently being handled may influence their depictions of pain. It may be inferred that the same might be true for how someone interprets and responds to works, according to their pain levels and associated mood. This adds another contextual layer to the interpretation of creative works. It may explain why this group of audience members do not find the works difficult to view or depressing.

The meaning of the exhibits, and the effectiveness at conveying this, is picked up on by audience members. For example, Kim (P-PA) notes the variation in how accessible works were for understanding the content and observes that this may relate to different motivations involved in creating the pieces – whether for personal reasons or in order to communicate experience. This may also be a case of subjective interpretation and some people finding certain styles of works more accessible than others, or preferring particular styles, as discussed above. Equally, the artist's intention might be for the meaning to be uncertain or following postmodernist beliefs that there is no single interpretation. Consequently, issues of interpretation make the communication process multifaceted.

Accompanying text:

Accompanying text labels are used to augment the creators' desired message of the piece. In some instances, this is to explain an abstract image's purpose or meaning, for example in the case of *Wascally Wee Willy* (Exhibit 1, p. 144), who writes of mutancy being in all of us. In others, text labels are used to develop the content or theme of the work, such as in the case of *Do You See What I Feel* (Exhibit 3, p. 148). Alternatively, text is used as an adjunct to the creative piece, adding biographical data or information about the creator's life, such as in the case of *Redacted Revealed Two* (Exhibit 19, p. 208).



Redacted Revealed Two

Penelope Clayden

Silk, Myrabilan, Porcelain, Wire.
Drawings: Charcoal and Ink on paper

Pain is a universal human experience. Penny's current work is an exploration of ways to create a visual iteration of chronic pain. She has extensive experience of pain, both personal and in her career as a nursing professional. As chronic pain becomes one with the body, taking up residence within the structure of soft tissue and bone, in her work fragile, hard ceramic becomes part of the cloth and cannot be seen as separate from the cloth once fired. Penny's pain feels black at times. Not all black is the same but she is using it as a metaphor for material ideas. It has levels which encompass many emotions which can be comforting but also depressing.

Exhibit 19 *Redacted Revealed Two*

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Some creators chose not to include text labels but, on the whole, did not state reasons for this; although one noted that they felt the work did not require it. As noted in Chapter Three: Method and methodology, in one instance I requested from a creator that I use an accompanying piece of text from their website to provide a context for the viewer. Audience responses regarding the abstract pieces and those works without text show that this decision was appropriate to support engagement with this work. I also felt that those audience members who were not concerned with accompanying text would not be affected by it, and this was confirmed by Rowan (NP) who stated on the VFF that they choose not to read any accompanying text. This individual's interpretative process (of not engaging with the accompanying text) may be due to their own art training and related professional work.

As Bourdieu and Darbel (1991) argue, those people who have not received training in art interpretation are 'condemned' to perceive in a work of art only a 'basic recognition of the object depicted' (1991: 44). This is likely to be linked to a greater difficulty in engaging with abstract works and a higher dependence upon interpretative tools, such as accompanying information or a broader context within an exhibition. As such, audience members who have had training in the arts are likely to have different interpretative processes and responses to 'lay' audiences. This applies to those creators with art training and the execution of their works too. Other comments about the interpretation of works confirmed that viewers appreciated having text labels for added context and because of their sense of responsibility to understand the creator's intention and experience. This suggests that the multimodal format of the creative piece with accompanying text were effective in communicating pain experiences, being drawn upon together by audiences, in the most part.

There is a contrast between the response to the visual work and to the accompanying text. For example, Alex (NP) observed that, in their opinion, the work *Buried Alive* (Exhibit 14, p. 177) had a 'teenage sketchbook quality' which they felt was off-putting, but 'the text made me feel bad about thinking that.' This observation demonstrates the difficulties for audience members in responding to works so personal in nature. A

sense of awareness of what the artist is feeling means that the assessment of the work itself is influenced partly by this. It may also be influenced by an awareness that the creator has written the accompanying text themselves. Consequently, the text may have a greater impact than if it was written in the third person or a more neutral manner. *Redacted Revealed Two* (Exhibit 19, p. 208) has text written in the third person and it did not elicit a particular emotional response from audience members. However, this may also have been the nature of the work as it was primarily a sculpture with drawings visible on a back wall in the photograph. On the VFF, Alex responded to the question (about reading the accompanying text labels) regarding a few other works, as well as *Buried Alive* (Exhibit 14, p. 177). This illustrates the importance of the text to this audience member, through their engagement with the question.

Alex (NP) commented of *Transformation* (Exhibit 9, p. 162) that the significance of the butterfly is not clear without the text, 'but interesting once it's pointed out.' Demonstrating that the imagery was not successful in capturing Alex's attention; however, the information about it was and the multimodal combination created an effective message. The text of *My Reality* (Exhibit 4, p. 149) was felt by Alex to be odd due to the description of devoting the 'craft to my pain, and animal rights.' Alex wrote, 'it felt like pain was personified and this was a dedication at the start of a book.' Of *Phoenix* (Exhibit 5, p. 152), 'I wouldn't have understood the significance of the different phases of the quilt without the text.' The disconnection between the accompanying text and imagery of *My Body* (Exhibit 11, p. 164) was picked up on by Alex (NP),

I was frustrated that there wasn't more connection between the words and the image. Why are there two bodies in the picture.

This remark demonstrates both an engagement with the image and wish to understand it further, as well as frustration at it not having a closer connection to the text featured alongside. While the text did not explain the imagery to audience members, it did engage people in the Facebook group where responses remarked

upon people not understanding what they cannot see and the 'striking' and 'powerful' imagery.

Text labels varied considerably in length and focus, with no apparent correlations with the style of creative work, duration or nature of chronic pain, and the choice of what to say, or how much information to include. Those text labels that focussed on the person (as opposed to the condition) might be said to add the individual to the pain expressed in the creative work. Together the work and text may unite the person and pain instead of experiencing it as something 'other' to the self, or as a dualism. Uniting the pain as part of the self may help the person to feel more in control of the condition, aiding mental wellbeing and management of their experience.

Their own personal viewing and interpretative process is described by Sam (C) who notes that, in viewing the exhibits, they look first at the work, not the title or accompanying text (where applicable). Sam stated that sometimes their interpretation was in line with the artist's meaning but in others this was only the case after reading the text. Interestingly, Sam (C) observes that they believe their 'original interpretation is due to my own personal experience.' Sam does not elaborate on whether their interpretation changes or whether or not they consider it be an additional or alternative interpretation, as opposed to incorrect. Although this may relate to Sam also being a creator and perhaps inclined to accept that creative works may be polysemic (be read in different ways by different people). It also demonstrates the role that being able to relate to a work personally may have on its interpretation and empathic response.

Empathy

Responses to the VFF question, of which works stood out and why, were most often related to the concept of empathy. This was commonly regarding pain, for example, '[Redacted Revealed Two, Exhibit 19] most closely connected with my actual feelings of

chronic pain' (Jo, P), or with the diagnostic process: '[*Hey Doc, have you figured it out yet?*, Exhibit 16] represents both my experiences with a continuum of symptoms and my diagnosis journey' (Taylor, P-PA). Additionally, empathy was elicited through the use of language or metaphors that the viewer could relate to, most especially where these related to items that people used themselves. For example, Jackie (P) wrote the following about *Struggles* (Exhibit 8, p. 160):

[Its] message was very clear, the use of shoes was brilliant [...] It's exhausting sometimes you need your sneakers – comfy and practical; sometimes you need your pretty shoes to be able to face the day

While Alex (NP) noted that the phrase 'breakable plastic' in *And Just What Exactly About Life Is Cruel?* (Exhibit 20, p. 213) was particularly powerful because 'it relates to something I've touched, been frustrated by, thrown away'. Alex (NP) noted interest in *Do you see what I feel* (Exhibit 3, p. 148) because it represented the experience of someone with a condition that is present in Alex's own family. Alex expressed a desire to better understand the condition, demonstrating a wish to increase empathy. The relevance of empathy to viewing the works is illustrated by Bryce (P) who commented, 'some relate to my own experience therefore will attract more attention from me and seem to stand out'. This suggests that having an empathic response creates a greater interest in some works. It may be that the participant was interested in how someone else expressed, explained or visualised the condition.

And just what exactly about life is cruel? (Stream of Consciousness)

Suzie Nugofsky

And just what exactly about life is cruel?

It took me seven minutes to pour the beans and grind them to the consistency of loam

And pour them into the hot water and cook them and press out the brown water and pour the fragrant liquid into the mug and take it by the handle and walk it over to the living room and hand it to you, who reclines on the couch, with a computer in your lap

Im in real pain

I walk softly on broken glass

The hips do the arthritic tango across rooms

Im hiking up stairs like theyre mountains and the kids can barely wait for carrot sticks but they sit there while twisting fingers and wiggling little butts because they see that it hurts

and they do hurt too

but the pain is in their arms and in the turning of their attentions from too much of this and too much of that and we each bite off a bit more that we can chew,

stuff it in with the replaceable spoon

that life keeps giving us because for some reason

we were meant to dine with breakable plastic and sometimes I think life is cruel for a such shoddy gift

Its the pain talking, I know that

I know life isnt a gift at all

its a series of rooms we all walk through, and eventually we leave one house and move into another and we keep this up forever because DNA is nomadic

Life is cruel when the mind is made small,

by ignoring a body

that is actually very content with the pain

the mind sometimes forgets, it doesnt need a home

Exhibit 20 And just what exactly about life is cruel?

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Empathic responses are demonstrated through a variety of comments regarding different works. The wider impact of pain on daily living was known to some audience members (including those who do not have chronic pain themselves), and they were able to recognise the authenticity of the representations in the works. For example, Pat (P) stated that *Disability 001-005* (Exhibit 15, p. 179) resonated the most with their experience of living with persistent pain, particularly the second panel, depicting being trapped within their own body and calling for help. Charlie (NP-PA) noted that the works ‘captured the emotions of suffering pain.’ Taylor (P-PA) commented on the exhibition that the works ‘are demonstrative of a plethora of emotions and sensations,’ noting the depiction of burning or sharp sensations but also of ‘shock, fear, despair’, representing the physical, psychosocial and emotional impact of chronic pain.

Empathy elicited through the work *Sciatica* (Exhibit 13, p. 168), and the role that some senses may play in chronic pain, are demonstrated by Angel (P): ‘when I close my eyes my body changes, parts shrink, others grow huge.’ Raj (P-PA) noted that the ‘burning nature of sciatic pain’ had been captured successfully. The use of red in *Sciatica* is commented upon by Sam (C) who makes reference to their own pain and relates to the sensations depicted in the artwork, ‘I definitely get that stabbing/throbbing/burning feeling all the way down my legs!’ The phrasing suggests that the empathy elicited is through having also experienced the condition, ‘I think she does a nice job describing that feeling.’ It is unclear how far this person would empathise with the representation if they had not previously experienced the same sensations. However, Jac (NP-PA) remarked that ‘the effects of disease and pain in the body are quite evident and striking,’ despite not living with chronic pain and having no known experience of the physical sensations of sciatica. These comments demonstrate that where symptoms and pain sensations are depicted overtly in the works, they can be communicated effectively, eliciting empathy in those who have and have not experienced the condition represented. This is also demonstrated by Taylor’s (P-PA) responses to *My Reality*.

Taylor (P-PA) states that the lines shown across the buttocks, in *My Reality* (Exhibit 4, p. 149), 'for me, represent the fragility of that part of my body.' The use of 'for me' is interesting as there is an implication that Taylor understands this interpretation may not be the creator's meaning and/or may be read differently by other people.

However, Taylor is able to construct an interpretation which relates to their experience of pain. This is powerful in demonstrating that the visual and creative expression of pain can communicate more of a pain experience than the artist's own meaning when creating the work. It also appears contrary to the responses to *Sciatica* (Exhibit 13, p. 168), which seemed to be more universal, including shared understandings of the sensations. It is possible that while some works are less overtly representing specific symptoms or sensations (such as the jagged lines across the buttocks in *My Reality*, Exhibit 4, p. 149), this does not remove the possibility for empathy to be elicited or an understanding of the experience to be constructed, even if it is not so clearly shared, as in the case of responses to *Sciatica* (Exhibit 13, p. 168).

The use, or absence, of colour in the works has been discussed in the previous chapter, sub-section 'Aesthetics,' regarding its application in expressing pain; it is shown to be effective in evoking empathy also. Commenting on the work *Phoenix* (Exhibit 5, p. 152), empathy is demonstrated when Sam (C) remarks that they relate to the work, 'having [fibromyalgia] myself.' Sam comments that they are 'still in the gray area,' not yet flying again, as shown in the artwork. This implies that grey is a colour not linked to the feeling of being able to 'fly', suggesting it signifies more negative emotions. It also shows the ability for Sam to project themselves into the work and its narrative, empathising with the content partly due to their interpretation of the use of colours. The use of colour in *Buried Alive* (Exhibit 14, p. 177) was described by a conference delegate as 'stark and bleak', reminding the individual of when they have been in severe pain: 'the world loses its nuances, just reduces to the pain and you.' Again, suggesting that the way in which colours are used (or not, as the case may be) influences the emotions elicited through the works and demonstrating the power to provoke empathy.

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Enjoyment of a work, or the presence of figurative design, are not necessary for an empathic response to be elicited. Jac (NP-PA) noted that, while not usually ‘a fan of abstract art,’ *Pain Abstract...* (Exhibit 2, p. 146) did lead them to feel ‘something very basic. Because of the colours used, I got the feeling of unhealthy skin.’ This suggests that colour itself may have a powerful effect in eliciting understanding and empathy. Likewise, materials and textures are used to achieve a specific effect in the works and aid the elicitation of an empathic response. For example, commenting on *My Reality* (Exhibit 4, p. 149), Angel (P) described their buttock as feeling as though it is ‘covered in facedown Velcro.’ The ‘combination of rigid and flexible elements [and] knotted fragments’ in *Redacted Revealed Two* (Exhibit 19, p. 208) are remarked upon by Jo (P) who stated that they were reminiscent of their MRI scans and how they imagine their own pain, demonstrating again the ability of materials and textures to evoke an empathic response.

The symbolism of *Phoenix* (Exhibit 5, p. 152) is described by Jac (NP-PA) as an ‘elegant way to convey the concept of pain as a disruptive element.’ Jac adds that it looks like a simple pattern but develops into something out of the ordinary, akin to a ‘subtle kind of pain that progressively transforms the individual.’ This observation, regarding the transformation of the individual through pain, from someone who does not live with pain, demonstrates an empathic response to the work, understanding the impact of chronic pain upon a person. However, Jac is a personal acquaintance of mine which may influence their interpretation, given that they have some awareness of my life with pain. This knowledge of life for someone with pain should not take away from the empathy elicited through the work as it may augment the response, rather than be entirely due to it.

The helpfulness of the works as a means to understanding others’ viewpoints, and experiences of living with pain, are commented on by audience members who have pain (whether or not they express it using creative formats). Hayden (C) noted that

pain is such an isolating experience, any connection to another can be a needed lifeline. I've discovered that not everyone "gets it" with art, but almost everyone can relate to the emotions. When I find someone that can use art to express themselves it is amazing to see, but that is not the purpose now, it's the connection to another person that is suffering in the same darkness.

This quote is given at length because it illustrates the depth of support brought about through the connection to another who can empathise with their experiences.

Additionally, it demonstrates the wish by creators and people with pain to help others to know they are not alone.

Participants noted their experiences of acute pain, or of chronic pain, but did so without wishing to deflect from the creators' experiences. For example, as mentioned above, Kim (P-PA) noted that they have back pain, adding 'but very mild in comparison to the exhibitors'. Some works provoked the sharing of illness narratives, for example, in response to *My Reality* (Exhibit 4, p. 149), Angel (P) wrote, 'That looks like my x-rays, I had a spinal fusion...'. Taylor (P-PA) wrote, in response to the same work, 'I love this piece too. I've had three spine surgeries...'. To *Do You See What I Feel* (Exhibit 3, p. 148), Taylor also wrote, 'I love this. As somebody with a number of mainly invisible chronic diseases, I can identify with the concept...'. To *Phoenix* (Exhibit 5, p. 152), Sam (C) wrote, 'Having FM myself, I totally get this!' before going on to give the duration of time that they have had the condition. The phrasing and punctuation suggest Sam is responding positively to the work as well as empathising with the message and content. This positive response may be evoked less through an enjoyment of the piece as art and more through finding a connection to the work and creator. The elicitation of illness narratives (or further details, such as specifying the duration of having the condition) also shows the way that the creative pieces were able to elicit empathic illness narratives.

In response to *Buried Alive* (Exhibit 14, p. 177), Angel (P) wrote ‘I have “cave days” when I feel like this [...] I feel like I understand the way the artist feels.’ Of *How do you feel* (Exhibit 6, p. 156), Hayden (C) wrote

I like this piece because it reminds me of confusion and chaos [...] trying to put some order and sense into life.

Taylor (P-PA) writes in response to the same work that they often adopt the bodily position shown in the work and would be interested to know what the artist is experiencing/representing. This suggests that the level of empathy is what elicits Taylor’s engagement with the work’s meaning and curiosity with regard to the artist’s feelings. Taylor had added in parentheses that they had ‘never had a question for an artist before,’ which demonstrated a different level of engagement with the work than they were accustomed to experiencing.

On a VFF Bryce (P) writes of *Out of the Box* (Exhibit 17, p. 192) that they could relate their own feelings of frustration with the work. The restrictions of limited mobility are referred to by Jo (P) on viewing the same work, stating that they empathised with the feelings of frustration, constantly needing to think about movements and being unable to do forms of exercise they previously enjoyed. Sam (C) recognised the influence of their own experience with pain on their interpretation of *My Body* (Exhibit 11, p. 164), writing ‘it could be because I have back pain and they represent something totally different.’ Consequently, the elicitation of empathy may influence interpretations as it may be a projection of personal experience with chronic pain. As creators stated that if the work provoked an emotional response then it has succeeded in its purpose, the reasoning behind the particular emotional response or interpretation is not of relevance (to them at least).

The subjectivity of pain

The personal and subjective nature of pain, and the experience of living with it, is highlighted effectively in the exhibition, according to Kim (P-PA). The individual nature of pain is picked up on by August (NP) when discussing that I, the researcher, have

chronic pain. August (NP) states that ‘no pain experience is [like] another’. While Alex (NP) states that they accept they ‘can’t get it,’ adding that it is unlikely anyone ‘who doesn’t experience it can totally get it,’ while wondering if two people with pain ‘can appreciate each other’s situation.’ Alex adds that being ‘pushed to the limits pushes empathy out’; demonstrating an understanding that empathy is not only difficult in extreme situations but may also be impossible under certain conditions, such as when experiencing pain. Whether this means you can empathise with pain, when not in pain yourself, is unclear. However, the findings here demonstrate that creators and others with pain (as well as those without) have empathised with the experience expressed in the creative pieces.

The subjective and unshareable nature of pain is also commented upon in the Facebook group, in response to the work *My Body* (Exhibit 11, p. 164). Sam (C) writes, ‘you can’t totally understand what you can’t see or feel. Even Dr’s struggle with this.’ The participant began their comment with the phrase, ‘This is so true!’ The exclamatory nature of the statement demonstrates the depth of feeling and empathy elicited through this work and its accompanying text. Hence illustrating both the connection to the work’s accompanying text, while also raising the issue regarding the extent to which it is possible for someone else to truly understand another’s experience of pain.

Knowledge about a condition which an individual has not personally experienced may be understood, by those living with chronic pain, as insufficient for authentic empathy. However, a health professional’s personal experience of living with pain is not known by patients in general and so erroneous assumptions might be made about the extent of another person’s empathy. This extends more broadly to the general public also. Given the knowledge that pain is a subjective experience, the question arises of to what extent it is possible for a person’s experience of chronic pain to be empathised with, by both those with and without personal experience of it. Equally, given the emphasis upon not displaying pain publicly, it may be the case that encounters between individuals with pain are occurring more frequently than people are aware.

The issue of achieving empathic communication with healthcare professionals is developed next.

Clinical encounters

Interactions with healthcare professionals are touched upon in the visitor comments. For example, Robin (PU-PRO), a medical professional, commented on the exhibits that related to their personal experiences at work. For example, *Hey Doc, Have You Figured It Out Yet?* (Exhibit 16, p. 191) is commented upon by Robin (PU-PRO) due to them having patients with unexplained symptoms, leading to the statement that they could therefore 'relate to the onus/burden on doctors to work out what's going on.' This is an interesting alternative viewpoint on the work showing a patient's 'diagnostic journey' (Taylor, P-PA) and illustrates the pressure felt by medical professionals to explain and identify causes for pain and symptoms. Robin (PU-PRO) also commented on the works *Sciatica* (Exhibit 13, p. 168) and *Pain Without Words* (Exhibit 12, p. 166), because of having patients with those conditions and therefore relating to the imagery. This links to Kelsey's (C) comment that creative pieces could be used as an additional piece of information 'towards the foundation of [a] diagnostic/treatment plan'.

In the Facebook group, Dylan (C) commented on the potential for the *Exhibiting Pain* project, suggesting that the medical community could be asked if seeing visuals created by those with pain would help increase understanding, the diagnosis process, and more broadly assist with treating people with pain. Sam (C) noted that they had previously taken an image into an appointment with a rheumatologist, going on to add that the doctor hung it on the wall and other patients commented that it was what they were trying to explain. Again, demonstrating that the use of creative works during interactions with healthcare professionals may aid the communication experience as well as potentially speed up the diagnostic process. It also reinforces the findings that some shared understandings of pain experiences are possible, as highlighted earlier through the work *Sciatica* (Exhibit 13, p. 168). A work shared in the Facebook group was described by Phoenix (C) as reminiscent of 'a scientific scan' and noted that it is

‘perhaps closer to doctors understanding.’ Interestingly, the person with pain who created the work is also a medical doctor which may have influenced the style of representation and they agreed with Phoenix that it did look like a scan.

The sharing of the works is described as validating what creators (and others with pain) have experienced and connects them to others, assisting other people in turn. Sharing works with patients has been shown to help build trust and for patients to know that they have an empathic practitioner, as described by Hayden (C):

They trust me, they find an empathetic person to relate to, and I am able to motivate them at a level I would not be able to otherwise (Hayden, C)

This demonstrates the strength of relationship that may arise through creating a shared understanding. Although it is important to note that this is Hayden’s description of their personal experience sharing works and experiences with patients and may not be received in the same way by the patients concerned. Consequently, the sharing of works may occur with patients, healthcare professionals, personal support networks or more broadly with the general public. However, this must be used in a productive manner and not as a contest of woes or in a way that leaves the patient feeling ‘if they can do... why can’t I...’. Nevertheless, in terms of feeling their pain is validated and experience understood, the trust and strength of relationship is likely to be established rapidly.

Sam (C) notes that Doctors know the medical information about a disease but cannot truly comprehend the symptoms unless they personally have to cope with it. Richards (2008) notes that her doctor had stated he knew her kidney transplant procedure would be painful because he had observed patients experiencing pain but had no knowledge of the severity or type due to lack of personal experience. This is symbolic of the larger lack of understanding regarding another’s pain but Richards states,

Had he been through kidney failure himself, he might have been more compassionate about his patients. This could have augmented his medical expertise (2008: 1719).

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I doubt that Richards is advocating that only people who have experience of particular conditions should become healthcare providers in those fields. However, the sentiment, together with Sam's (C) comment, does show the sense experienced sometimes by patients, that their doctor has no true understanding of their experience and the possibility that this contributes to a breakdown in effective communication.

I am conscious that this a complex issue which may work well for some patients and professionals but not for others. It may trigger a sense of guilt or anxiety in the patient for not being able to do the same as the professional. It may also increase difficulties with feeling misunderstood or not believed if they are unable to achieve the same as the professional.

Personally, I encountered a registrar who, on hearing that I had resigned from my full-time office-based job, proceeded to tell me about his own pain experiences and reprimand me for stopping work, without asking about my plans for alternative employment. Likewise, Ellingson (1998) notes a conversation about losing weight with her orthopaedic consultant who related his own experience doing so, explaining 'that he simply decided to eat less, and that's what I need to do as well' (Ellingson, 1998), demonstrating his lack of empathy and sensitivity to their different situations.

Consequently, I am mindful that there are concerns regarding professionals sharing their personal pain experiences with patients. This also made me wary of disclosing my own pain with participants. In the position of researcher, I could be deemed to have 'power' and did not wish to take away from participants' pain experiences, as highlighted in Chapter Four, The Pained Researcher.

Further thoughts about *Exhibiting Pain*

The final VFF question concerned further thoughts about viewing the creative works in *Exhibiting Pain* and the potential for such projects. Responses from those without pain were focused primarily on the study in general, noting that it was a ‘stimulating project’ (Bernie, PU) and an ‘excellent concept’ (Rowan, NP). Also, on the exhibition as a whole, praising it, in part, for being easily accessible and free (Charlie, NP-PA). There was a query about the lack of poetry (Ali, PU) and another about the feasibility of a collaboration between artists to create ‘a more universal understanding of pain, or is it just too individual?’ (Alex, NP). An audience member also expressed the emotional impact of viewing *Exhibiting Pain*:

Honestly, I think its mostly difficult to view as you feel the persons pain acutely. Does that help? If it helps ease that persons pain even for a limited time then it is worth it. (Billie, NP) [sic]

This raises important implications for the emotional responses to viewing for audience members, as highlighted in Chapter Five: Ethical considerations. However, it also demonstrates the willingness of people to view the works, despite the distress they may cause. This may link to audience members’ feelings of responsibility to interpret works ‘correctly’, showing a sense of duty linked to the viewing activity.

At my instigation, a discussion of the effectiveness of an online exhibition to share the experience of pain took place in the Facebook group. Responses varied between comments relating to ‘the first preference’ being for a physical exhibition (Jude, P), but also recognising the benefit of more people being able to access it online. Sensory difficulties are referred to by Kelsey (C) regarding their use of a smartphone to view the exhibition, noting that this made viewing online rather inaccessible. This demonstrates that while the online method, and convenience of being able to view using different technologies, may be helpful for many people (and increase engagement), it can create alternative access issues for some.

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Bernie (PU) commented on the exhibition as a whole:

This is an outstanding exhibition, and very meaningful way of engaging with the difficulty of conveying the notion of embodiment and pain in a creative and engaging way

These views were demonstrated through others' responses to the viewing of the works also. For example, Bryce (P) asked if the creators' doctors understand their condition and if 'their families and friends understand their struggle.' This question suggests that the participant, who lives with chronic pain, may experience such difficulties themselves, or at least understand the possibility of doing so. It may also suggest that Bryce was considering whether the creative works helped the creators' acquaintances to understand their pain and therefore if this may aid Bryce to communicate their own experiences with friends and family. Alex (NP) asked about the nature of pain in the creators' identities, whether communicating it via creative works helped to explain it and what aspect surprised them, that someone without pain might not imagine. It is likely that these questions and level of engagement with the experience of life with persistent pain are influenced by a wish to understand their own family member's pain, illustrating the potential for exhibitions and creative works to aid this process, as well as triggering thinking around the topic more broadly. Ashley (C) wrote of viewing the creative works:

I expected and found that it resonated with my own experience of making creative work about pain. It's not easy viewing but is very powerful.

Ashley's comments again demonstrated that the viewing experience may be difficult but felt to be worthwhile, as well as evoking empathy. August (NP) commented in the Facebook group that they had a social work student relate an experience about being upset at seeing a woman's physical pain. Prior to the *Exhibiting Pain* project, August stated, they would have responded to the student that it is not possible to see someone's pain, but now has more confidence in the possibility of sharing more than words about pain.

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When considering a positive outcome from the *Exhibiting Pain* project, Mel (P) noted that, as a result of the group, they have been able to use art to communicate their pain. Adding,

When I share the art, I am able to convey my feelings surrounding pain. In the past, I felt scared & definitely stuck.

Mel adds that it is inspiring and a privilege to view others' art about their pain. This sense of respect to the creators for sharing their works is shared by other respondents also. The sharing of pain experience is noted as a particular positive from the research by Mel (P):

One positive thing to come out of this for me is that I no longer feel I am alone in my struggles And most importantly, I can communicate what the pain is like via showing my doodles, & others' amazing art to friends

While a creator, Phoenix, expressed gratitude for having been part of the *Exhibiting Pain* research project:

I really appreciate your interest and pursuing this research, and giving me this opportunity.

Together, these aspects demonstrate that both audience members (with and without pain) and creators benefited from viewing and sharing creative works. They were also grateful to be able to share these with others, to support the communication of personal pain experiences.

Conclusion

What has been shown here is that the creative works have generated a range of responses to the pain experiences represented. The works have encouraged discussions and thinking around the topic of living with chronic physical pain, increased awareness, broadened perspectives about how the condition may be expressed and elicited empathy and validation of the experience. The accessibility of the works, as mediators of the chronic pain experience, is linked to issues of interpretation. Motivations in creating the works are also influential, for example if the works are to demonstrate particular symptoms then physiological reference points and colour

choices become more significant. However, where the works are expressing something broader about a change to self, the invisibility of the condition, or the isolation arising from living with chronic pain, then accompanying text may be more important if the work is to be interpreted 'accurately', according to the intended meaning. That said, the accuracy of a reading of a work has been shown to be of greater concern to audiences who do not have chronic pain than to the creators of these particular works.

Accessibility of the work is more broadly linked to the style of work, perceived skill and the presence, or not, of title and/or text accompanying it. Equally, this is influenced by audience methods of viewing and engaging with the works, giving thought to the meanings possible, drawing on personal experience and knowledge, and preferences for particular styles of art, among other things. Therefore, the accessibility of the work in order to communicate the chronic pain experience is dependent upon multiple factors linked to subjectivities of the audience, such as their own experience with pain or knowledge of art. This raises the question of whether creative works can reliably be used to communicate the experience of pain but this is equally linked to ideas of what needs to be 'reliably' communicated, by whom, to whom and with what purpose. Next, my final chapter will bring together key points from the two findings chapters and demonstrate how these link to the literature discussed previously. It will also be shown to what extent this research project has been able to address the gaps in research, as well as making recommendations for future research and practice.

Chapter Eight: Critical reflections

Introduction

In this final chapter I provide a wider discussion of the findings presented in chapters six and seven, together with the theoretical arguments underpinning the thesis. The unique contribution to knowledge made by this thesis will be outlined. It is argued that a contribution to the literature has been made, regarding the creative expression of life with chronic pain, the use of social media in carrying out research (and associated ethical considerations) and the value of online exhibitions of creative works for people living with persistent physical pain. Some reflections on my role in the research process will also be presented. Limitations of the research study will be discussed and proposals made of future research areas of value. I begin by addressing the research questions this study sought to investigate.

Research Questions

Findings are presented here with regard to the three key research questions. These are concerned with how audiences interpret creative works about life with pain, the benefits of sharing such pieces and the use of online exhibitions to do this. When addressing each question, I provide summaries of key findings discussed earlier to show how they contribute to knowledge in these areas.

What may be learnt from audience interpretations of creative representations of chronic physical pain?

It has been shown that, regardless of whether or not audiences live with pain and/or participate in creative activities, it is possible for them to respond empathically to creative representations of life with chronic pain. Postmodernism argues that there is no one 'correct' interpretation of a creative work, and that multiple readings are all equally valid. However, some audience members were concerned that they should understand the meaning of the work 'accurately,' according to what the creator

intended to convey. It was found that audience members who do not live with chronic pain were most concerned with interpreting the works 'accurately,' feeling a sense of obligation to do so, recognising the personal and sensitive nature of what is being shared. For this audience type, the accompanying text was of particular importance in guiding interpretations. Findings showed that creators did not require their own works be interpreted according to the meaning they had in mind when making the piece; nor were they concerned with the perceived accuracy of their interpretations of others' works. Participants agreed that artworks generally do not need to be interpreted – instead, the elicitation of an emotional response meant that the work had achieved what it was intended to. As a group, audience members with pain, like creators, were less concerned with their interpretations of the works according with the creators' intended meaning; instead, they were found to derive benefit from being able to project their own experiences on to the works.

A limitation in the nature of the research was that the sample size of participants was small and, thus, did not allow for a meaningful analysis breakdown by biological sex of participants, cultural differences, age, or duration of pain, though this information was gathered from those participants who completed consent forms. The Visitor Feedback Forms [VFFs] and Facebook data allowed for an examination of broad responses to works, enabling an analysis of how the aesthetics in the creative works were seen to be expressing the pain experience. For example, it has been shown that there was a broad acceptance of red as a colour denoting pain and that grey was seen to suggest depression; a lack of variety of colour was considered as showing a struggle to live well with pain. Specific symbolism in the works was not generally explored by participants in their feedback, except occasionally in passing, and this was mostly when they felt it was unclear – for instance, questions were raised about the symbolism of crosses in *My Body* (p. 144). However, overall responses to works showed that the style of work and perceived level of skill in its execution were influential in how audiences engaged with the pieces and their perception of the pain being represented.

Motivations, both in creating works and viewing them, were recognised by all participant pain-types as influencing the expression of pain within the work and how the piece may be interpreted by a viewer. For example, if someone is viewing to understand more about a particular condition, symptoms and/or to contribute to a diagnosis, or for a more general view on how chronic pain affects a person's life, this will affect what a person expects to see in a work, what they look for and their engagement with accompanying text. Those people who do not have creative interests or knowledge were more concerned with reading accompanying text than were others with such a background. Text was also relied heavily upon by those people who do not live with pain, in their pursuit of understanding the work 'accurately.' Overall, specific interpretations were found to be less important for all participants (whatever their pain status) than were the benefits to be gained from the sharing and viewing of works, which are considered next.

What are the benefits to sharing creative expressions of life with chronic pain online?

Benefits to sharing creative expressions of pain, identified through the research, included that the sharing of creative works online facilitated engagement with the topic of life with chronic physical pain. Participants with pain (whether or not creators) observed that benefits included being able to identify with the works, reducing their sense of isolation. They also noted that they were able to use the works to help explain their own pain experiences to people they know. Some stated that they were planning to use creative techniques to show their own pain as a consequence of viewing the works, showing that audiences felt this was a potentially helpful way to express pain.

While there were concerns about the possible distress to be caused by viewing a collection of creative works on the topic of life with persistent physical pain, there have been benefits demonstrated through the elicitation of empathy and validation of the pain experience. Additionally, some audience members (specifically those with pain, whether or not creators) found comfort in viewing the works, because of finding they were not alone in their experiences. Those who shared the works benefited from

feeling that they were providing comfort to others with pain by helping them to know that they were not alone in their experiences. Sharing the works online enabled a broad audience for the works, heightening the sense of achievement with regard to reducing isolation for others and gaining recognition of personal experiences. Some creators commented that they generally do not share their works with people and do not feel a need for them to be interpreted, some specifically stating they do not like their work being subject to interpretation. However, in taking part in this globally accessible research project, many chose to participate, or at least be a member of, the Facebook group, which meant that they could see others' interpretations of their works. This suggests that the potential benefits to sharing the works, and the perceived need for chronic pain to achieve greater recognition, was considered of greater importance than these previously-held personal preferences. This emphasises that the sharing of works enabled creators and other pained audience members to feel heard and to gain validation of their pain experiences.

Can an exhibition of creative representations of chronic pain increase understanding of the experience of the condition?

This research has shown that online exhibitions were successful in engaging audiences in the topic of life with chronic physical pain. The exhibitions were shown to elicit empathic responses and engagement with the topic. This helped to enable validation of the pain experience for those with pain (those viewing and those sharing their works). It is possible that the creative format of the works encouraged other people (without pain) to engage with the topic in a way that may differ markedly from their usual approach when responding to people wishing to talk about their own pain.

Audience members who live with pain were the group who most frequently highlighted (via the VFF) that their views about life with pain had been challenged or developed. This suggests that the works were helpful in supporting people to think beyond their own experiences of pain and it may be that they were broadening their ideas on how to explain and express persistent pain. The exhibitions were described as being somewhat difficult to view by some audience members who do not have pain.

However, those with pain (including creators) experienced comfort in viewing in them. The inclusion of a larger audience group drawn from health-care fields would have been interesting, in order to explore whether the exhibitions helped to develop their empathy and understanding of what it is like to live with persistent pain. However, it has been clear that both gallery sites have engaged audiences for various reasons. They have provided support and comfort, as well as eliciting empathy and facilitating a greater knowledge of the way in which chronic pain can affect the lives of those who have the condition.

Reflections on the method

Content of the creative works about pain is influenced by the intended audience for the pieces. This was one reason that it was important to me to use works which predated the research project, instead of having some generated for it, as I anticipated that the content would be influenced by the expected audience. This decision regarding the method ensured that the works were more 'authentic' representations of what people who use creative activities wished to express through this medium about their pain. In addition, this approach allowed for an examination of who the intended audiences were and how this may influence the representations, as well as considering who creators wished to express their pain to.

The use of online exhibitions in this piece of research, to gather interpretations and generate discussions (in response to creative representations of pain), provides both an innovative research method and new data. To date, research on the interpretive experience and the interpretations themselves (in response to pain related creative works) has not, to my knowledge, been published. Likewise, concerns regarding possible misinterpretation, and creators' responses to the sharing of their works, had not been explored to date. The intention has been that such data would aid insight into how persistent pain is understood by audiences with differing pain statuses, profiling of which was made possible through demographic surveys of participants who completed the consent form. Additionally, the method applied here enabled

exploration of the role that creative representations may have in facilitating understanding of life with persistent physical pain.

Use of public exhibitions to strategically raise awareness are advocated by Han and Oliffe (2015), who support Chung et al. (2009, cited in Han & Oliffe, 2015) in the recommendation for online exhibitions, promoted through social media, to increase the reach of the works featured. While exhibitions have been used for dissemination of findings in the fields of arts-based and visual research, and have been used to raise awareness around health conditions, they have not been used to specifically collect data as a method in the field of health research (to the best of my knowledge). It was of interest to know if such an approach could be used successfully to gather research data. While refinements to the method would be recommended for future studies taking a similar approach, I believe that it has been successful in enabling me to address the research questions, as demonstrated above. Recommendations for refinements would include considering having the galleries 'open' for data collection for a much longer period of time to encourage comments to be received on specific works.

Mayne (2015; 2017) used a Facebook group to conduct research into the wellbeing of women sharing images of their yarn-based creations online. Writing of the use of Facebook to carry out the research, Mayne notes that participants liked being able to engage with questions at their own pace, selecting to what extent they responded and how much they shared about themselves, as well as how much to respond to each other's comments. I believe that this was the case in *Exhibiting Pain* also. In addition, not having a restrictive schedule for participation ensured that there was flexibility for people to participate as they wished, around any fluctuations in their health. Linked to Mayne's (2017) comment about managing comments, as a sole researcher there was a lack of support in managing the *Exhibiting Pain* group. Had the group been larger and more active, or more comments made on the WordPress site, this would have been difficult to manage. Additionally, if I had, for example, taken annual leave or become seriously unwell during the data collection period this would have been complicated

and could have led to lower retention or engagement. Consequently, I would advise future research with similar methods either to consider 'back-up' or assistance in moderating the group, or to provide clear information to participants about planned breaks and time-frames.

Findings have shown that the VFF was a helpful and successful way to gather responses to the works shown on the WordPress site. As discussed in Chapter Seven, sub-section 'Participation in *Exhibiting Pain*', of those who clicked on the VFF on the WordPress site, 9% returned a completed form. This was not a high response rate but it did demonstrate a level of interest in the content of the form. Given the level of academic interest in the method itself, it is not known how many respondents clicked on this with an intention to submit the form, rather than to satisfy their curiosity regarding the research *per se*. Following feedback from two participants, I updated information on the site to forewarn people to avoid clicking away from the VFF page as it led to loss of content. However, this problem may have deterred people from returning to complete the form if they had lost content and demonstrates a limitation in the data available as well as the method.

Comments were obtained on specific exhibits in the Facebook group but allowing this method to develop in a pragmatic way led to the group evolving into an asynchronous focus group. In addition, the group became a forum for people to share their own creative representations of pain, even if they were not in the original set of exhibits. The benefits to this allowed people to take a level of ownership over the group content and, while it was clearly set up as a research focussed group, it enabled people to use it as a forum to find support and share their pain experiences creatively. Mayne had a similar experience in her Woolly Wellbeing Facebook group (exploring wellbeing through the sharing of woollen crafted items online). One of her participants stated:

Facebook is a really powerful tool for collaboration... look at us all! [...] positive rewards from interacting with one another (Mayne, 2017: 71)

Having not specifically set out to achieve this level of community or support via the Facebook group, lends greater weight to the finding that it developed in this way. It is illustrative of the need experienced for such support from others living with chronic pain. In addition, it demonstrates the way in which the sharing of creative works is able to unite people with chronic pain into a perceived community, addressing the sense of isolation experienced by those living with the condition. In discussing the use of a closed Facebook group for research, Mayne notes that the risks of security and confidentiality were acknowledged and discussed in the group but that the gains of forming a community were seen as more valuable (2017: 71). Together, the ethical issues of consent in arts focussed and social media-based research is complex and requires a level of pragmatism, combined with common-sense, thoughtfulness and transparency.

Reflecting on the experience of using this method to collect data, I recognise that I could have taken a less pragmatic approach. Rather than allowing a natural evolution of the research method, specific time frames could have been set and a schedule developed for posting questions into an online focus group to encourage active engagement. However, levels of engagement were maintained throughout the data collection period and I believe that not having a time-specific period ensured that people did not feel pressured to log in and participate. Instead, a more informal approach enabled them to contribute as and when they wished and were able. This is akin to how Cornish describes the methods used in 'Communicating Chronic Pain', noting that the researchers came to refer to their approach as 'imprography – an improvised choreography that starts with some parameters, but flows and evolves in response to participants' engagement' (Tarr et al., 2014: 42). Given that chronic pain (and associated chronic fatigue) is a condition which fluctuates somewhat unpredictably, I believe that this was the appropriate way to carry out the research as it allowed people to participate as they felt able, perhaps increasing the chances of them doing so. Again, this accords with Cornish's description of their approach, nothing that as life is 'open and changing, can't research methods allow for openness too?' (Tarr et al., 2014: 42). Another aspect to this approach is that it made space for

my own chronic pain and fatigue flare-ups by not being constricted to a strict schedule. That particular issue highlights another aspect of carrying out research using social media which is the need to be able to take breaks and manage the potentially time-consuming nature of checking multiple comments and responses in the group.

Online methods

Reflecting on the use of online methods, as discussed above, an alternative way to carry out the research would have been to use a fixed period of time, most likely a fortnight, for the discussions. This would have allowed participants enough time to contribute but not so much time as to risk the loss of momentum. This is supported by Deggs et al. (2010) who found that their six-week online focus group experienced a steady drop in responses and interactions after the first two weeks. Using this approach would have required more structured moderation than the method used. This is because it would need a tighter semi-structured interview approach, but should still have generated data exploring interpretations in social media exhibition environments.

As ideas of what is public-private in online environments can shift, Giaxoglou (2017) writes that ethical issues may be best addressed by utilising collaborative forms of research practice. Those contributing become akin to partners in the research rather than subjects or participants. Consequently, they are in a position to share with the researcher their understandings of interaction in a particular context (Giaxoglou, 2017). Arguably, this occurred in the negotiation of what was acceptable to reproduce from the group between Chris (NP-PA) and Dylan (C) who wrote about their experience in considering audience interpretations of their artwork in the Facebook group.

Benefits to using an online medium for data collection may have included it enabling people to leave and return as they wished to. Additionally, the effects of viewing potentially distressing content may have been mediated by doing so on an electronic device (computer, phone or tablet) rather than in person, as a screen is placed

between the work and the viewer. However, sensory issues with viewing on a screen were also identified by participants and a preference was clearly asserted for a physical exhibition. That said, one participant noted that, as a very private individual, they appreciated being able to view the works online as opposed to in a physical gallery. It is possible that, given the public-private dualistic nature of living with pain, this is a sentiment that might be applicable more broadly. Not only is the expression (and the decision to do so) fraught with this conflict, but the viewing and listening to pain may also be, with it being felt more acceptable or manageable to do so in a private setting than in public.

The role of an exhibition

Museums, or exhibitions more broadly, can facilitate the recognition of people and stories previously not given voice, allowing them to take on a role as a force for activism (French, 2019). Silverman argues that museums have potential as therapeutic agents (2002), which I believe is demonstrated by the benefits found to arise through *Exhibiting Pain*. Cox and Boydell (2016) argue that the arts have the potential to capture public interest in a range of health-related topics. Such approaches can stimulate public engagement and change attitudes and behaviour (Cox & Boydell, 2016). This is demonstrated through Dodd's (2002) discussion of images of artist Jo Spence's experience with breast cancer which are described as being neither clinical nor abstract but presenting a sense of the reality of the condition. I believe it has been shown that online exhibitions were successful in engaging audiences in the topic of what it is like to live with chronic pain.

The way in which images may affect viewers is dependent on the larger cultural meanings which they invoke and the context (social, cultural, political) in which they are viewed (Sturken & Cartwright, 2001). Consequently, the meanings are not inherent to the image itself but achieved through the viewing and interpretative process. This results in multiple meanings which are created anew each time the work is viewed (Sturken & Cartwright, 2001). However, when works are being viewed in a museum context, the institution's curators have decided what is displayed, how, and with what

intentions. In this way, museums can shape debates by choosing who or what to include and exclude (Sandell, 2007). While the works in *Exhibiting Pain* were not in a formal gallery or museum, I made deliberate efforts to avoid deciding what was featured and how it was discussed in accompanying text. This was in order to attempt to avoid shaping interpretations through curatorial decisions as far as possible, as well as in order to give voice to those sharing their works. I believe that this ensured that the voice of the person with pain was made stronger and they were given space to express what was most important to them. This may have strengthened empathic responses by bringing the creators voice into the exhibitions more directly than if carefully curated by me. The acceptance of multiple interpretations and the decision to avoid shaping the narrative around the works are both representative of the postmodern epistemology underpinning this project.

Analytical approach and theoretical frameworks

Given the novel research method, using social media hosted exhibitions to collect data, the approach to analysing material was somewhat pragmatic. This was due to being uncertain of the quantity or nature of the material that would be obtained. Consequently, a composite approach was adopted, as discussed above in Chapter Three, sub-section 'Data Analysis'. This was intended to optimise the 'bitty' nature of the data to achieve an understanding of the expression and interpretations of the creative works.

The pragmatic and composite approach to data analysis, together with the underlying epistemology of postmodernism, meant that a traditional framework through which to analyse the findings was not adopted. Postmodernism calls into question the construction of theories and their assumptions (Alvesson & Skoldberg, 2018). While rejecting meta-narratives (totalising theories), as discussed in Chapter Three, postmodernism focuses on the multiplicity of truths. As chronic pain is experienced subjectively, the meanings attached to it are also individual and subjective. Pain, and the reporting of it, may fluctuate and change, according to social context, over time and in response to other factors. There may therefore be multiple meanings and

narratives to any one person's experience of their pain at any one time, as well as to the meaning an outside person may place upon that experience. As such, it is important to recognise the changing, subjective and polyphonic nature of these pain experiences (Kugelman, 1997) by not attempting to apply an overarching meta-narrative to them.

Although I chose not to apply an established meta-narrative in the analysis of findings, the relevance of stigma (Goffman, 1963), and Goffman's ideas on the presentation of the self (1959), have been shown as pertinent to the experience of chronic pain and the public revealing of it (in Chapter Two, sub-section 'Stigma and impression management'). The concepts of frontstage, backstage and performance have particular relevance to the difficulties of managing the conflict inherent in the public and private nature of living with chronic pain, discussed in Chapter Six, sub-section 'Public-private dualism'. In addition, a focus on the narrative represented, and its interpretation, may have helped to develop ideas around illness narratives in a visual and creative context, but this was felt to be restrictive following previous preliminary work in this area (discussed in Chapter Two). While I decided not to rely on these theories to analyse the data, on the basis of the postmodern epistemological approach, I also decided against it for other reasons.

Apart from one creator's reference to stigma (Exhibit 11 *My Body*), the concept did not occur in the accompanying texts to the work, nor did it arise within the findings as a significant theme. It is likely that this may be, at least in part, due to my omission to ask a question specifically relating to the topic. It may also be due to the combination of my role as the researcher, together with my beliefs about stigma and personal experiences of living with chronic pain. I am uncertain why, but historically I have not engaged with the concept of stigma as being of great pertinence in my own experience of chronic pain (see personal reflection below). In this sense, it is possible that my role as an 'insider' researcher has limited the theoretical potential of the findings by underestimating the significance of some concepts, such as stigma. However, I believe that it has also allowed for an authentic analysis of findings from the viewpoint of a

researcher who lives with pain, without the emphasis of placing established theoretical frameworks on to new data. Instead, the postmodern rejection of meta-narratives, together with my own reflexive approach to data collection and analysis, has potentially allowed other themes to be highlighted which may otherwise have been overlooked.

It is possible that my rejection of the relevance of stigma is through a repudiation of it in terms of personal denial and for self-preservation. Or, my interpretation of the experiences that others class as stigma, I have classified under some other name or understanding. Equally, it may be due to having experienced chronic pain since childhood, rather than adult onset. At the time of writing these ideas are unresolved for me and I continue to contemplate the topic.

Reflections on having been the pained researcher

It was shown in Chapter Four that there is a need to include the voice of those with chronic pain in the academic field relating to the topic. Consequently, this is what I have attempted to do through the inclusion of my own experiences and reflections over the course of this thesis (and research). There is now a need to reflect on my own role as a researcher with pain when considering the research undertaken here as a whole. Pain cannot be removed from this equation because it is a persistent presence in my life. While I may have reached the same findings without my own knowledge of what it is to live with chronic pain, the inability to remove pain from the equation demonstrates the need to acknowledge this in the research process. It cannot be switched off and my insider/outsider status, while not clearly delineated in any research situation, is even less separable in the instance where the very thing that makes you an 'insider' demands to be heard and cannot be separated from the self or

researcher. As such, I have found myself questioning whether this invalidates the findings I have reached. For example, wondering whether these are projections of myself and personal experiences. If so, I question whether this makes them less valid for others living with chronic pain or those supporting people with the condition. As it is argued that living with pain cannot be understood by those who do not do so perhaps there is value in the researcher also living with pain. de Montalk (2019) asks if is she drawn to the writings about pain because she has it; do they communicate so effectively to those who do not live with chronic pain. Likewise, I may ask if the findings identified in this project would communicate so effectively to those people who do not have chronic pain.

While the data here demonstrates that pain *can* be communicated to others, the level of someone's understanding cannot truly be known. However, this does not take away from the elicitation of empathy and validation which is possible through the use of creativity. Nonetheless, I question whether, as a researcher with pain, I am suitably positioned to assess this. I wonder whether I feel that the research has effectively highlighted concerns *because* I have pain and I question whether these are really my own concerns all along, which I am projecting on to the data. As chronic pain without aetiology leads us to question our own bodies and selves (Gotlib, 2013), so it leads me to question my engagement with the research data produced through this study. However, I believe that this questioning of myself and my own possible biases strengthens the findings because it demonstrates that I have applied a reflexive approach and maintained self-awareness throughout the research process, putting measures in place (such as utilising supervisions to discuss findings and my possible partiality) to avoid an over reliance upon my personal experiences.

Reflecting on the process of having been 'the pained researcher,' I recognise the unique contribution and potential limitations that this has placed upon the research presented. Regarding the emotional impact on me, it has been difficult to accept that my story, or autobiography, has relevance (or is of interest) outside of my immediate social network. Therefore a process of acceptance and personal recognition of the

value of my story has been required. In a society that values 'good pain' (Kugelman, 1997) and restitution illness narratives (Frank, 1995) over the 'boredom' (Jackson, 2005) of a never ending chronic pain narrative (Kugelman, 1997), it is not easy to put forward a personal chronic pain narrative without feeling a sense of concern for the reader. As Daudet wrote, there is a responsibility to consider the audience receiving the pained narrative (2002). The process of telling my story here has led me to reflect on what I chose to include and why, how I framed my experiences and responses. As Kugelman (1997) notes, there are many 'I' positions in the telling, it is a never-ending story, not only because my pain is persistent but also because of the continually evolving and devolving meanings I attach to the experiences, and the ongoing changes in aetiology, treatment and life impact. My story is incomplete and it is told from a specific time and place. I can relate that at the age of four and a half I announced to my Mum that I had 'tooth ache in my hips,' but I do not recall that moment. Consequently, her telling of the event forms part of my narrative and story. The memories I have of pain sensations are intermittent, as pain exists primarily in the present moment. Therefore, my relaying of it is based on memory, hindsight, or the meanings I have constructed through my frequent tellings and re-tellings. The story, like the pain, is constantly evolving. The pain I have in the here and now as I write plays a similar role; it influences the memory of pain past and expectations of pain future. Consequently, my identity as a person with pain is never fixed and needs to be understood as one interpretation, in one moment and social context. If this is true for me, it is important to consider the relevance of this for the creators and audience participants also. The creative works are polysemic, holding many meanings, depending on who is viewing, in what context and when; this includes the context of their experiences with chronic pain to that date. In turn, the viewing of the works may influence the person's interpretation of pain, and how to express it, in the future.

The vulnerable researcher:

In Chapters Four and Five I highlighted some concerns about the vulnerabilities of novice researchers and responding to difficult situations during the research process. While I feel confident that training received through former employment, for example

in safeguarding and for lone workers, meant that I was equipped for some issues encountered in fieldwork (though not entirely applicable to my online method), I was aware that some of my colleagues had not undertaken such training. The principles of common-sense should provide sufficient safeguarding actions but not everything can be anticipated and I do feel that this is an area for consideration by universities in their doctoral training. For example, conversations about the revealing of safeguarding concerns, understanding the University's policy regarding these and what actions the researcher should take are all important factors to be considered in providing training to researchers, particularly doctoral students (including, for example, what they should state to participants before interviews begin regarding confidentiality in the event that something is revealed which gives cause for concern).

Biography, autobiography and auto/biography

An area of the research which would benefit from development elsewhere is the nature of the multiple biographies involved in *Exhibiting Pain*. Participants, both creators and audience members (with and without pain), bring to the research their own biographical experiences. By participating in the research, they drew upon their own experiences to interpret a creative work, representing another person's experience of their own pain. What is interpreted as a meaning of a work may evolve through the experience of viewing the works, as understandings evolve. The creator's story now includes sharing their creative piece(s) in a research exhibition. This weaves their biography with mine as researcher, and to the other participants (Cotterill & Letherby, 1993). For those in the Facebook group, this has included seeing others' interpretations of their works, and therefore their pain, often for the first time. Being part of the group may affect participants' own understandings of their pain, influencing the narrative they go on to tell about it (and consequent creative works). Some participants noted a new intention to use creative techniques to represent their own pain. Others mentioned that they now thought about what they were trying to convey and how someone may interpret it. For some, the experience allowed them to feel part of a community, with a shared understanding of pain and its creative expression. Therefore, there is the potential for the creative works to show an altered

sense of self as a person with pain. Both the representation of the work, and its interpretation by the audience member, are carried out in a particular social and temporal context. As such, each is impacting upon the other's biography through the weaving together of these experiences and the interaction; they become a part of one another's story. Brennan and Letherby's (2017) proposal of a auto/biographical continuum is pertinent here.

As noted in Chapter Four, when writing about themselves, but acknowledging other peoples' significance, academics could be described as creating an '*auto/biography*' (Brennan & Letherby, 2017). While writing that is about others, but which recognises the biographer's subjectivity, makes '*auto/biography*' more appropriate. Brennan and Letherby suggest that the use of a 'continuum' recognises that

concentration on the *self* OR on the *other* is not clear cut and that, whether consciously or unconsciously 'slippage' often occurs [sic] (2017: 157)

Such a continuum allows for entanglement between the self and other, as touched upon above when considering the nature of interpreting creative works in *Exhibiting Pain* and the future works that may be produced by participants. Arguing that auto/biography is academically rigorous, Brennan and Letherby highlight that it enables the author's role in the process of constructing, rather than discovering, the story (or findings, in this context) to be made clear.

In this sense, my role as a reflexive pained researcher has allowed me to show the influences of my *auto/biography* upon the research process. For example, where my personal experiences or beliefs about living with pain have influenced the nature and form of the research topic, questions asked (or not asked, as the case may be) and interpretations of findings. My own biography as a researcher with pain was also discussed with participants to allow transparency in the research process. This may have influenced how they saw me, as an 'insider,' and affected what they chose to reveal, or how. The research process, and its writing up, encompass *auto/biographies* of participants, which in turn influence my own story. In addition, the contribution of

my personal acquaintances illustrates another way in which our pre-existing biographies interacted in a new way, through the research process. This potentially changes the nature of the research as well as the relationship between us. The degree to which any, or all, of these factors can be separated is unclear, making Brennan and Letherby's suggested continuum a useful aid to thinking about the levels at which such biographies are interacting.

Multimodal communication of pain

It was in response to the inadequacies of language that Padfield (2003) first worked on creating a 'visual language' to represent chronic pain. Hurwitz (2003) argues (in the Introduction to Padfield's photographic monograph, *Perceptions of Pain*, so not without bias) that visual depictions of persistent pain can enable viewers to grasp, visually and emotionally, the nature of the invisible and subjective experience, potentially leading to improved care. Although Hurwitz notes that there are few depictions in art by people with persistent pain, Antelo (2013) asserts that Frieda Kahlo's art (which represents her own pain) may provide physicians with a means to better understand 'the experience and dehumanizing consequences of pain' (2013: 464). Cox and Boydell (2016) argue that the arts are powerful mediators in understanding and experiencing health and wellbeing, which supports Antelo's (2013) argument that Kahlo's works are a medium through which to visualise pain and its effect on the person. Together these arguments suggest the potential to reach people through this means of communicating pain. The participant August (non-pained [NP]) observed that Kahlo's art has been used in talks they have attended, demonstrating the validity of Antelo's (2013) argument and the potential for creative pieces, such as in *Exhibiting Pain*, to be used likewise. Indeed, the requests I received to use the work *Pain Without Words* (Exhibit 12, p. 166) in conference posters and presentations emphasises this point.

The innovative and varied methods applied in the 'Communicating Pain' project by Tarr, Gonzalez-Polledo et al. (2014) led Tarr to argue that:

no one method of producing versions of pain tells the whole and complete story. [...] Alternative methods, producing alternative versions, are important, as is hearing these versions in dialogue with one another (2018: 242)

Consequently, Tarr appears to be arguing that multiple methods help to elicit different aspects of pain experiences and such findings should be taken in combination to more comprehensively understand pain (2018). I believe it is reasonable to assert, following this, that the expression of chronic pain through a multimodal format, such as the creative representation, with accompanying title and/or text (if applicable) and co-speech gestures, can help to create a more nuanced understanding of the experience. Linking this with individuals (perhaps clinician and patient) using it as a tool to talk about their pain experiences, similar to Padfield and Zakrzewska's work (Padfield et al., 2010; Padfield, 2011; Padfield et al., 2015; Padfield & Zakrzewska, 2018), enhances the multimodal format of communication and is likely to create a more comprehensive understanding of the experience of pain for that individual, as well as eliciting greater empathy and validation.

I believe that this is representative not of a 'shattering' of language, or of a shortage of the 'right' words, but of language being experienced by the person with pain as inadequate to communicate the multidimensional and subjective condition they live with. An enhanced multimodal format to express aspects of life with chronic pain may be experienced as more effective because it is likely to feel that a more comprehensive expression is achieved. Drawing upon creative representations, together with accompanying text or speech and possibly co-speech gestures, may allow the individual to feel that they have conveyed a broader aspect of their experience and therefore achieved more effective communication. This argument is supported by Gonzalez-Polledo and Tarr (2014) who argue that new forms of expression of chronic pain on social media have 'reconfigured' pain communication, by joining together people with pain into 'networks of multimodal communications' (2014: 13). While this statement is made specifically in reference to expressions on social media, it demonstrates that the flexibility in mode of expression can unite people with pain and communicate their experiences.

As noted earlier (in Chapter Two), Jackson (2005) suggests that at least part of the reason people do not wish to hear about someone's chronic pain is because of the boredom it elicits. There is a level of emotion work (Hochschild, 2012 [1983]) entailed in both the telling and hearing of such a biography, in order to withstand the feelings generated. Emotion work is also involved in providing a suitable 'performance' to the audience, who in turn must respond appropriately. I believe that some of these feelings and hindrances are overcome through a multimodal expression of the pain experience. I suggest, for example, that engaging the 'audience' with a creative representation focuses attention on an object, releasing the narrator to focus on the key message they wish to convey, and removing attention from how (in)visible their pain may be at that time. The creative element to the expression allows an audience member to bear witness to the pain in a way which is novel. Having an object to focus upon can help to ease the discomfort of the story for both audience member and narrator. As such, the creative work, accompanying description, behaviour and co-speech gestures can meld into what is deemed to be a 'credible' performance. In turn, this allows the narrator to feel that they have received recognition and legitimization of their condition, which is crucial to their inherent sense of self as someone living with pain, and who potentially may feel stigmatised by it.

While greater empathy and recognition of experiences may be facilitated through the creative works, a question remains over whether it is the *pain* or the *life with* pain that is made visible and/or knowable. As someone who lives with chronic pain, I am inclined to say that perhaps the two things are inseparable and that an attempt to draw a distinction between them would be erroneous. However, this question does seem relevant when considering participant responses to the nature and content of some of the creative works exhibited. For example, Kim (a participant with pain and a personal acquaintance of mine [P-PA]) noted that some images were more positive than expected while another participant (Chris, NP-PA) noted surprise regarding how 'elegant and subtle' some of the content was. These comments relate perhaps to expectations that more of the pain symptoms would be represented and/or an

assumption that to live with pain is to suffer, with little or no positivity likely to be expressed in the works.

The possibility and implications of misinterpreting creators' works arose in the Facebook group and was discussed in Chapter Seven, sub-section 'Interpreting works'. The ethical implications of a similar point are discussed by Cox and Boydell (2016) who note concerns regarding a mental healthcare project which used dance as a research dissemination strategy. Audience feedback showed that aspects of the dance were interpreted in a different way than intended and risked perpetuating stigma, rather than reducing it. However, the research team concluded that the performance enabled a dialogue to occur with the audience (2016). In relation to the works and interpretations in *Exhibiting Pain*, concerns about misinterpretation arise in the opposite manner. The creators were not concerned about (mis)interpretation but audiences without pain were anxious to interpret the works 'correctly'.

Expressing pain

A sense of changed identity following the onset of chronic pain, together with embracing the pain into the self, links to the conflict experienced regarding invisibility of the condition and the implications of this. In turn this is related to whether people talk about their pain. One creator (Sam) noted that their pain is not something they raise with people because it is as much a part of them as the colour of their eyes. This raises the question of whether they have accepted the pain as part of their identity or perceive it as separate or 'other'. As one participant (Alex, NP) asked, how does this relate to the person they are 'at their core'. Given that pain fluctuates, perhaps the essence of it as part of oneself does so too. If one is 'pretending' *not* to be in pain, is the pain being denied as part of the identity, or hidden or othered. Additionally, is this denial occurring by the person who has the pain only or is the pain also being ignored or denied by others around them. In turn, this leads me to question if this mean that others around the person do not see the pain as part of that individual's identity and I question what role their acceptance of the individual's pain has. These conflicts and difficulties may be part of the reason that obtaining validation and empathy can be so

difficult. It is also part of the public-private dualistic nature of living with pain and the conflict inherent to what to express, when, how much and to whom.

For those people who find art and creativity inherent to their ways of expressing themselves, they may be less aware or concerned with the ability of an audience to engage with the work or to interpret it. The creators' lack of concern with specific interpretations suggests that the very act of expressing their pain experience is sufficient for them and the act of sharing the work is secondary. Creators (and other creative participants with pain in the Facebook group) stated that they do not generally share the works with people they know (only a few mentioned sharing them with specific people in their social networks) but do so more widely (either on the *Exhibiting Pain* sites, PAIN Exhibit site or their personal websites). This apparent contradiction aligns with the conflict identified in the findings regarding the public-private dualistic nature of living with pain and whether or not to share the pain, as well as how to do so effectively.

Bobby (P) observed that those in the Facebook group 'turn [pain] into something'. There is clearly a link being made here between pain and the potential of creativity to act as a transformative and cathartic force. Creativity is shown to be used by people with pain in multiple ways. Clift and Camic (2016) noted that the arts provide skills in creative problem-solving and such abilities may help in creatively learning to manage pain. Accordingly, rather than restricting use of the term 'creativity' to apply to the creation of an artwork, piece of poetry or likewise, the term is also used by participants to refer to the ways in which they adapt to and manage chronic physical pain. Frankie (C) writes of creativity as a way of experiencing new situations and finding ways to adapt to a life with chronic pain. The use of creativity has also been shown in the findings to help people in learning to accept their pain, as well as to manage it, for example when Sam (C) writes of their creative works helping them to accept the pain was not only in their head.

Viewing and interpreting pain

Published research regarding differences in the representations of pain according to intended audiences has not been identified to-date. However, this study has shown that where the intention was to create an image which illustrated the location or nature of particular symptoms or pain, the work was generally created for a specific audience and included physiological references. On a more general level this research has explored who creators had in mind as audiences for their works. As discussed in Chapter Six (sub-section, 'Audience for the works'), the intended audiences were mostly stated by creators as being themselves or for no one in particular. However, often there were underlying contradictions in the answers or secondary audiences given, such as, being for those who do not live with chronic pain, or, for others who do live with chronic pain so that they know they are not alone (see Figure 11 Creators' audience in mind for their work, p. 169). I believe that this apparent contradiction concerning the intended audience is linked to the public-private dualism involved in living with chronic physical pain. It demonstrates, as other findings discussed above have, that while the instinct is to not express the pain publicly (hence the initial comments of no intended audience or it being for themselves), there is another inclination which is linked to seeking validation and empathy. The choice of creating the work, and the decision to share it, is also linked to the provision of empathy and support, as demonstrated by creator comments that they wished for others to know they were not alone. This is shown to be successful through responses in the Facebook group which refer to seeing the 'shared experience' (Pat, Participant with pain [P]) and seeing that others 'get it' (Sam, creator [C]).

Carlin and Cole (2011) note that objectifying pain, locating it outside of the body and thereby making it dialogical, makes it a conversational partner that is also a symbolic representation of ourselves. They observe that at first Padfield's images, in *Perceptions of Pain* (Padfield et al., 2003), seemed 'a bit curious' because it is only possible to make sense of them within the patients' testimony, which can make the images 'powerful, and even chilling and disturbing' (Carlin & Cole, 2011: 117). Carlin and Cole go on to state that it is striking that Padfield makes the case that pain destroys language as 'her

images need words to be understood' (2011: 118). However, I would argue that this may show not only how the images and language can work together but also suggests that the authors may not experience chronic pain themselves. It may be that the ability to empathise with certain images is related to an ability to project our own experiences on to the works. This is similar to de Montalk's (2019) questioning of whether the language and storytelling of the writers she had studied, or the fact that she was also in pain, had been of greater influence on her in writing about her own pain. Alternatively (or, additionally), it might be that Carlin and Cole (2011) were focused on 'correct' interpretations of the work, for the individual whose pain is represented, rather than recognising the potential for, and eligibility of, multiple interpretations.

The time and context of the interpretation are relevant, as are those of the creation of the piece. Guillemin (2004) observes that because the interpretative context is not fixed, the representation of an illness is understood at that point in time. This has particular pertinence in the case of chronic pain where the condition commonly fluctuates, with symptoms changing and cycling through 'good' and 'bad' phases. Reynolds (2002) notes that artists in her study recognised changes in the work they had produced during the course of illness. Reynolds (2002) noted that changes in the works included, for example, choices of colours or image. Potentially, a series of works created over the length of time might form some sort of illness narrative about chronic pain. Consequently, the pain represented becomes contextually situated, as does the interpretation of the work. However, this does not prevent the work from having the potential to elicit empathic responses. For example, Padfield and Zakrzewska argue that the materiality of the photographs used in their research, as well as the images' ability to document, facilitates empathy and validates the pain experience (2018: 217). In keeping with Padfield and Zakrzewska's argument, it has been shown in findings presented here that the creative works were successful in eliciting empathic responses.

Data obtained through both the Visitor Feedback Form [VFF], and in the Facebook group, was focused on issues of (mis)interpretation, the sharing of the creative works and motivations for creating and viewing them. This consequently moved away from specific interpretations and details of the representations themselves. In this sense the collection of data was somewhat pragmatic as I developed questions in the Facebook group in response to lines of thought during the ongoing analysis taking place alongside. This allowed for discussions to form around the topics which appeared to be of most interest to members of the group, such as the concept of creativity, the benefits of sharing the works and viewing them, and how creativity had helped people with pain. I believe that this allowed for discovery of topics of particular interest to the participants which helped to retain their engagement. In addition, it was of interest to me to know what it was about the creation and sharing of representations of chronic pain which interested the participants themselves. As a consequence, the topic of sharing the works became of greater importance in the findings than I think it might otherwise have done so, allowing for identification of the concept of public-private dualism in chronic pain. This approach, and the discussions around the sharing of the works and being part of the Facebook group, elicited the topic of gratitude also.

Gratitude was expressed at different times in the research process and by different groups. For example, participants with pain were grateful to those sharing their works for helping them to feel less isolated, creators thanked me for the opportunity to share their works and both those with and without pain thanked the creators for sharing something so personal. I believe that this outpouring of gratitude is influenced by the sense that usually no one wishes to know or listen to experiences of ongoing pain, as demonstrated by Sörensdotter (2013) and Sheppard's (2019) reports of participants stating the trouble they had in finding people willing to listen and of the relief when doing so. This is supported by Clarke and Iphofen (2008) who note that the effect of a patient's account of their pain being believed cannot be underestimated as patients express gratitude, relief and surprise in response. I suggest that this is one reason that the sharing of the creative works is valued so highly by creators, because it forms a

validation of their pain, together with the responses garnered, and the act of sharing is equivalent to finding people willing to listen.

The finding of people willing to listen, and who believe the pain experience, is also reflected in the sense of community which is provided through participation in the Facebook group and through viewing either gallery. For example, one participant with pain (Pat) referred to 'our community' when commenting on the importance of giving voice to those with chronic pain and the viewing of the WordPress gallery. This connects to Daudet's (2002) comments on the pleasure and relief of finding others who understand. In this sense the Facebook group in particular helped to address some of the social isolation experienced by members living with chronic pain.

Mayne (2017) reported that the Woolly Wellbeing Group was experienced for some as a supportive community and there was recognition of a 'common bond'. Participants felt part of a community that provided cheerleading on completing a project, friendship and support (Mayne, 2017). Anecdotally members of *Exhibiting Pain* have likewise reported forming new friendships, finding it to be a safe space and valuing the inspiration they gained from seeing others' works and meeting people who are like minded. Both sites have continued to receive interactions and contact is made with me to say how helpful they are, which created an ethical issue regarding their possible closure.

An ongoing ethical issue arose out of the support people have found from viewing the works and the community of the Facebook group. Writing about a drama representing experiences of women with breast cancer, Sinding et al. (2008) note that at the end of the tour, the ethical question had become whether they should end it. Some people, they write, saw the benefit it brought to audiences and felt they wished to continue to honour those represented in it. In the case of research carried out using online methods, Lunnay et al. (2015) argue that researchers must be diligent in removing research material when the project has been completed and ethical approval ceases.

Tailored approaches may be appropriate for research that benefits participants, particularly where it has given voice to participants in a way that suits them (ibid.). In the case of *Exhibiting Pain*, there had been a number of comments in the Facebook group, on the Visitor Feedback Forms and via personal communications to me about how helpful and supportive the sites had proven, so I was reluctant to close them. Following discussion with my supervisors I decided to continue the Facebook group and WordPress site. I notified the creators of this decision, requesting that they let me know if they wish for their work to be removed. I also offered them the opportunity to include additional works (and/or details of their own websites) now that I did not need to restrict it to one per person. In response, no one wished to take down their work, four requested their website addresses be added and two had additional works posted. I also discussed the continuation of the galleries with the chair of the OU's HREC committee and she felt that it was fine to proceed. I will continue to assess this and close them if it seems more appropriate in future, which is in keeping with the approach already taken in responding pragmatically to such issues as they arise.

Developing the *Exhibiting Pain* research

In this section I explore identified limitations in the research undertaken here, together with suggestions for how this work may be developed in future research and clinical practice. As has been shown by de Montalk (2019), and my own reflective contributions to this thesis, the researching of and writing about pain can affect one's own pain physically, as well as the psycho social emotional impact of doing so. I wrote that 'pain begets pain', in Chapter Four, when writing and reading about it. This leads me to wonder how the action of depicting it creatively differs, if at all.

Potentially the element of catharsis to be gained through the action of creating can help to redress negative impacts. As Stuckey and Nobel (2010) state, creative methods can be used to facilitate communication and enable cathartic release. However, while creative flow may enable catharsis and distract from the pain sensations, a possible limitation to its benefits occurs if pain interrupts the flow. As shown by participants,

such as Cam (P), who spoke of pain blocking their creativity and stealing the best of them (Chapter Six, sub-section 'Creative Activity'). Periods of creative blocks may terrify, writes Batmanghelidj (2016), because the person may feel that their lifeline to pro-social functioning is denied them (2016: 222). Creative flow may not always be smooth because of pain, whether that is consciously being represented or not. Consequently, this may form a limitation in this approach to communicating the experience, however it may be the case that for some people the activity is a therapeutic distraction, providing pain management benefits.

All but one of the 23 creators had a prior interest in the arts at some stage of life, or to some level. Consequently, it is not surprising that many describe art as their natural language, because they have a long-standing interest in it. People who do not have the same history or level of engagement with the arts may experience a sense of being intimidated, have a fear that they lack the appropriate skills or knowledge, or may not have an interest in using this as an approach to express pain. They may also experience frustration and difficulties if the creative work produced does not appear to be an accurate reflection of their experience, as described by Jolly (in Tarr et al., 2014). From the perspective of audiences, people with similar concerns may be reluctant to engage with such methods as a way to learn about life with pain. As discussed above, creators agreed that if a creative work elicits an emotional response in the viewer then an interpretation was not required. However, creators commonly described art as a 'natural language' for them and therefore an innate way in which to communicate their experiences, whether language was experienced as inadequate or not (only two creators mentioned the inadequacy of language to convey pain). There was little mention by creators of difficulties with language, for them it was more that art is their natural form of expression and they emphasised making *visible* the pain and their experiences with it. This does not address however the way in which audiences respond to the work if art is not a 'natural language' for them. As shown earlier, levels of knowledge about art may influence the way in which audiences engage with certain pieces or styles. For example, a lack of knowledge or education in the field may create difficulties in engaging with abstract works and/or those without interpretative text. As

pain is a subjective and individual experience it follows that the coping mechanisms will be equally subjective and individual. Creative works may not help everyone to understand the experience of living with pain but, when used as part of a multimodal approach to communication, some fears about audiences' lack of knowledge or interest may be overcome.

As the creators in this project had strong interests in art and creativity, prior to the onset of their pain, they were naturally drawn to express their pain in a creative manner. Jolly describes that in her experience of the 'Communicating Chronic Pain' project, those participants who seemed more at ease with non-textual communication found the process helpful (Tarr et al., 2014). However, for others such communication was difficult. It may be that such approaches to communicating pain are more successful for those who are more naturally drawn to creative forms of expression, as suggested by the creators who participated in *Exhibiting Pain*. In turn, works created specifically for the purpose of expressing pain to particular audiences, or to be shown in exhibitions, or by those people not so innately drawn to creative forms of communication, may elicit different responses by audiences as they may present their pain in alternative ways. In turn, these points of difference may connect to the perceived levels of skill in creating the works which has been shown in findings here to affect responses. Consequently, these points may provide interesting concerns for future research.

The findings of this research provide insight into audience reactions when viewing creative representations about pain. It demonstrates that the multimodal format elicits empathic responses and it would be helpful to consider how this may translate to the use of visual and creative tools in clinical encounters, such as those used in Padfield et al.'s work (2015, 2018). Further research encompassing the use of creative works (made by the individual themselves) in clinical encounters would be helpful to see if this strengthens the democratising nature of communication that the use of visual cards was seen, by Padfield et al. (2015, 2018), to have in appointments.

Unique contribution to the field

Findings presented here may have relevance to the work that Padfield and colleagues (Padfield et al., 2010; Padfield et al., 2015; Padfield & Zakrzewska, 2018; Semino, Zakrzewska, & Williams, 2017) are carrying out, in creating a visual tool to aid communication between clinician and the person with pain. A greater understanding of the ways in which creative works are interpreted or elicit empathy may aid the refinement of using them as a tool in clinical interactions. In addition, this research has shown that certain styles of works may engage different people, or mislead them about the levels of pain the individual experiences, and it may therefore help to think about the range of styles or techniques that might be used in visual clinical communication tools.

Padfield co-created images with patients (2011) but the sole creation of a work by the individual personally may not only hold cathartic benefits and aid pain management (due to distraction enabled through the activity) but also facilitate a personal acceptance and validation of the individual's own pain experiences. As shown by Birk's (2013) discussion of needing to 'play-act' her credibility for others, validation of pain can be required internally as well as from other people. Failure to recognise an individual's pain can lead to doubt and subject them to stigma (Quintner & Cohen, 2016). Health professionals, the person with pain, and their families may begin to doubt their own judgements about the pain. Interestingly, Gotlib (2013) notes that such doubt of a person's reality of pain leads to envy of those with visible symptoms of a health condition, adding that the person begins to doubt him/her-self. Internal validation was demonstrated in the findings by Angel (P) who described that the sketching of their hand helped them to re-evaluate its difference and facilitate acceptance. Additionally, Sam (C) spoke of the expression of pain as an image having helped them to personally accept the pain's validity and that it was not 'in their head.' As Thompson (2016) writes, 'making sense of pain includes both internal and external

validation’ (2016: 311) and this appears to be achieved, at least in part, through the creative representation of pain experiences.

No words are sufficient to capture a true and complete understanding of a phenomenon as multifaceted as pain, writes Minden (2005); adding that ‘language and speech are always in some way out of control’ (2005: 270). Images and creative, multimodal, formats of communication may be more appropriate in trying to express experiences of living with chronic pain and I have shown here that they are effective in eliciting empathy and engaging peoples’ interest. Stewart (2016) argues that images extend beyond linguistic restraints, enabling interpersonal access to inner feelings and beliefs. Images also facilitate

a sense of connection from within an otherwise isolating and chaotic internal pain experience. Words are limiting but art elicits an emotional response (Stewart, 2016: 347)

Scarry (1985) suggests that part of the difficulty in communicating pain is due to the lack of an external object to focus upon. Consequently, the creation of images or creative works representing life with persistent pain may help to address this and form an effective means of entry into others’ worlds. Indeed, Padfield and Zakrzewska (2018) note that through the process of patients co-creating images of pain, a ‘different type of language and vocabulary around pain’ was generated (2018: 213). The process of image-making, as well as the images themselves, moved conversation away from stories or histories, towards specific aspects that individuals wished to communicate about their pain experience, such as isolation (2018). It has been shown that this is also the case in the works featured in *Exhibiting Pain*. For example, the works do not depict medical histories or illness narratives *per se*, instead they often focus more on the nuances of living with chronic pain, such as its invisible nature (for example, Exhibit 3, *Do you see what I feel*, p. 148) and how it transforms the self (as seen in both Exhibit 5, *Phoenix*, p. 152, and Exhibit 9, *Transformation*, p. 162). This shows the ability of creative works to communicate many aspects of the experience of chronic pain.

Implications for clinical practice

As touched upon in Chapter Six, sub-section 'Creative Activity,' Cam (P) had noted that the keeping of creative works acted like a diary. The act of keeping works or doodles in a diary implies a chronicling or record of pain, as opposed to keeping a collection or portfolio of works. Creative works representing illness have been shown to change over the course of time (Reynolds, 2002) and it may be possible to observe a process of 'biographical disruption'³¹ (Bury, 1982) in the adjustment to and acceptance of pain in a series of works (as is depicted in the individual work, *Phoenix*, Exhibit 5, p. 152). This hypothesis is supported by comments in the Facebook group which refer to a 'creative journey' and changes in the content and styles of works over time³². Sam (C) asked in the Facebook group if others journal with their art, going on to say that they had tried written journals previously but never felt able to accomplish what they wanted. However, Sam does not state what it was they wished to accomplish with the journals. The use of creative pain journals may be worth considering for those people who feel that creativity is a more natural form of language for them. It would be worth introducing the idea of presenting their pain in creative formats in pain management programmes, with initial support to do so. As some participants noted, they were already participating in creative or artistic pursuits but had not previously considered representing their pain in this format before viewing the *Exhibiting Pain* works.

It may equally be the case that assessment tools of pain should be developed to utilise visual techniques or representations. Although this may raise concerns around the interpretations of the works and how subjective these are. However, as Padfield et al. (2015, 2018) have demonstrated that the use of visual aids in clinical encounters can aid communication this may not be a significant problem. The assessment tools might still aid discussion around the pain experience, levels and sensations, as well as what

31 Bury (1982) describes the adjustment to the onset of illness and change in anticipated life plans as a biographical disruption.

32 As this was discussed following the closure of data collection, I am reporting it as anecdotal evidence, without names or references.

the pain means to the individual, without a need for a universal understanding over how the creative work is to be interpreted.

In order to contribute their own voices to their medical records, in keeping with a person-centred approach to care, it may be appropriate for people to include copies of their creative pieces in their medical records, or submit them alongside disability benefits applications, as a way to add personal evidence and their own voice to records. In addition, such works may be used to aid discussions around the impact of certain activities on their pain and improve the quality of interaction between clinician and the person with pain. Connected to this, Jolly expressed uncertainty about the extent to which non-textual communication of pain can increase understanding of suffering (Tarr et al., 2014). I would respond to this concern that there should not be a reliance upon a visual creative representation to communicate in isolation, rather it should be used as part of a multimodal form of communication for those who feel able to do so. This links to Jolly's observation that the offering of a space in which these forms of communication can be expressed can be therapeutic in itself (Tarr et al., 2014).

As touched upon earlier, social networks of people living with pain also seek understanding of the pain experience and how best to support the individual. The contribution of my own acquaintances in this research highlighted the wish of people to understand more about life with pain and how to support people with the condition. In addition, other audience participants noted an interest in viewing the works to learn about particular conditions or the experience to enhance their understanding of how pain affects those they know. Consequently, this demonstrates that there is interest and scope in exploring how creative works may help to enhance understanding and communication between those living with pain and their support networks.

Impact of *Exhibiting Pain*

One benefit of carrying out research using online galleries is that I have been able to witness the impact of the research which, like the galleries, has proven to be ongoing. I was contacted by a pain management nurse in Canada to say that the programme with teenagers she worked on traditionally used creative techniques as a way to manage their pain. However, following her viewing the WordPress site she had introduced the use of creativity as way for teenagers to express pain and an end of year exhibition in the hospital gallery. All of which contributes to them gaining college credits. One member of the Facebook group gained confidence through the support received after sharing a work there that they went on to exhibit it in a public, physical, exhibition. Presenting the work at The British Pain Society's Annual Scientific Meeting in May 2018, I was flattered to receive two prizes for my conference poster. These were the Committee's choice and the People's Choice award. I believe that these demonstrate the value and potential that delegates perceive for the work, both in clinical settings and more generally for people living with pain. In addition, I continue to receive messages and emails in response to people viewing the works, noting how powerful and helpful they are. These messages, and being able to witness the immediate impact of the work, have helped to motivate me and reminded me of the relevance of the research when enthusiasm ebbed.

Conclusion

This research set out to explore whether creative approaches to communicating chronic pain can successfully increase understanding of the condition, in addition to considering what the benefits are to sharing and viewing such works, as well as the potential for exhibitions to aid this process of increasing awareness, reducing a sense of isolation for those living with persistent pain.

I have been able to use the experience of this unique online method to make recommendations regarding approaches to digital methods and ethical practice for

future research following related techniques. These have included recommendations on how to strengthen data gathering methods on Facebook as well as considering the use of online exhibitions to collect responses to the works featured on the two platforms used. Additionally, issues have been highlighted considering the ethical use of online methods and visual works, including the difficulties of viewing potentially upsetting material. I have shown that it is important for universities to consider the way in which they support potentially vulnerable, novice, researchers when responding to difficult situations or participants, with a need to also consider safeguarding concerns for both researcher and participants.

I have shown that while the methods applied here were not straightforward, there is potential to develop these further to create stronger techniques of data collection. Using my own experience of living with chronic pain, I have been able to draw on these reflections to help me to consider the underlying issues arising in the data gathered. This has demonstrated the contribution that a researcher's own *auto*/biography can make when exploring a topic. I was able to draw upon personal experiences of living with chronic physical pain to inform the research topic, method and to inform findings. Additionally, the use of my personal acquaintances as research participants, in a transparent and reflexive manner, has enabled me to consider how those people who are close to individuals living with pain may also be supported through the use of creative representations of pain to aid understanding and empathy. This has also enhanced the different levels of biography at play in the research.

Creativity provides an alternative and/or an additional means to express pain, which may help to facilitate communication of the experience of living with chronic pain. However, there are considerations on whether the perceived level of skill or style used will affect the responses to the works and this is something that should be borne in mind for creators if they wish to express something specific about their pain. That said, the cathartic release, public acknowledgement and objectification of pain may be sufficient in terms of benefits experienced by the individual, as well as the product providing a tool to aid communication. This shows that the multimodal communication

of pain, through creativity, accompanying text or speech, and co-speech gestures can create a powerful form of pain expression, overcoming the experience of language as inadequate to convey a life with pain. This enhanced expression of persistent pain is effective in eliciting empathy and, in turn, aids recognition of the individual's experience, through validation of their pain. When a person with pain feels that they are unable to articulate their pain, because of the reluctance of others to hear about it or bear witness to it, creative representations form a bridge to facilitate a way to communicate that is deemed acceptable by both parties. The sharing of creative expressions of persistent pain may help people to overcome the conflict of the private and public dualistic nature of living with pain, wishing to achieve empathy for their situation but feeling unable to express their pain experiences to others. Additionally, the works provide a resource to help others talk about, ask questions, and explain the experience of living with chronic physical pain. The achievement of this research is best summarised by repeating the words of Mel (P):

One positive thing to come out of this for me is that I no longer feel I am alone in my struggles And most importantly, I can communicate what the pain is like via showing my doodles, & others' amazing art to friends [sic]

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Appendices

Appendix i: Participant demographics and exhibition visitor details

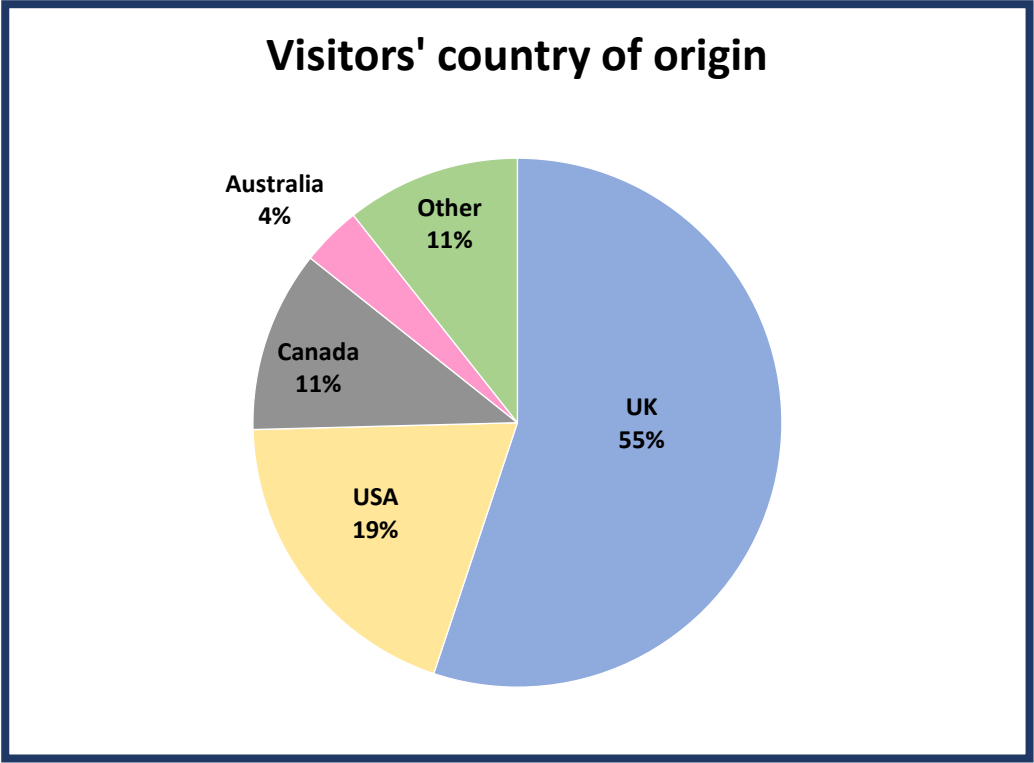


Figure 14 WordPress visitors' country of origin



Figure 15 Members of the Facebook group who were active participants

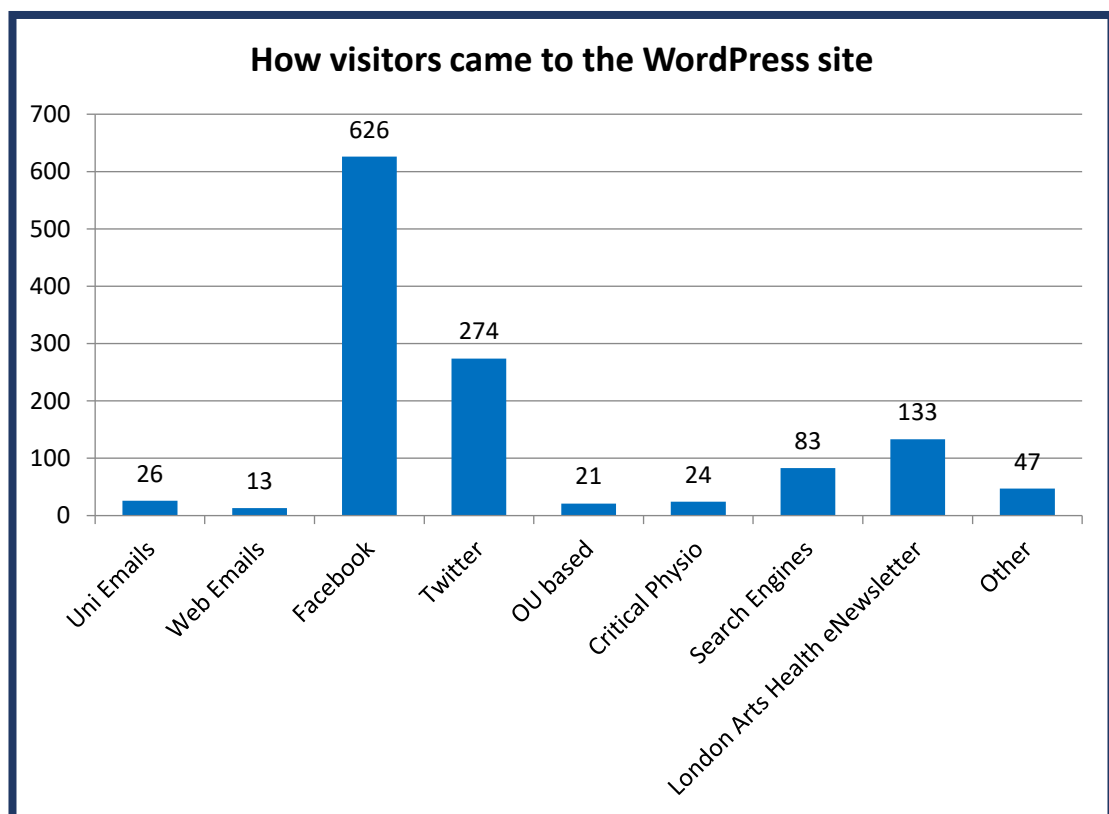


Figure 16 Referrer used to reach the WordPress *Exhibiting Pain* site

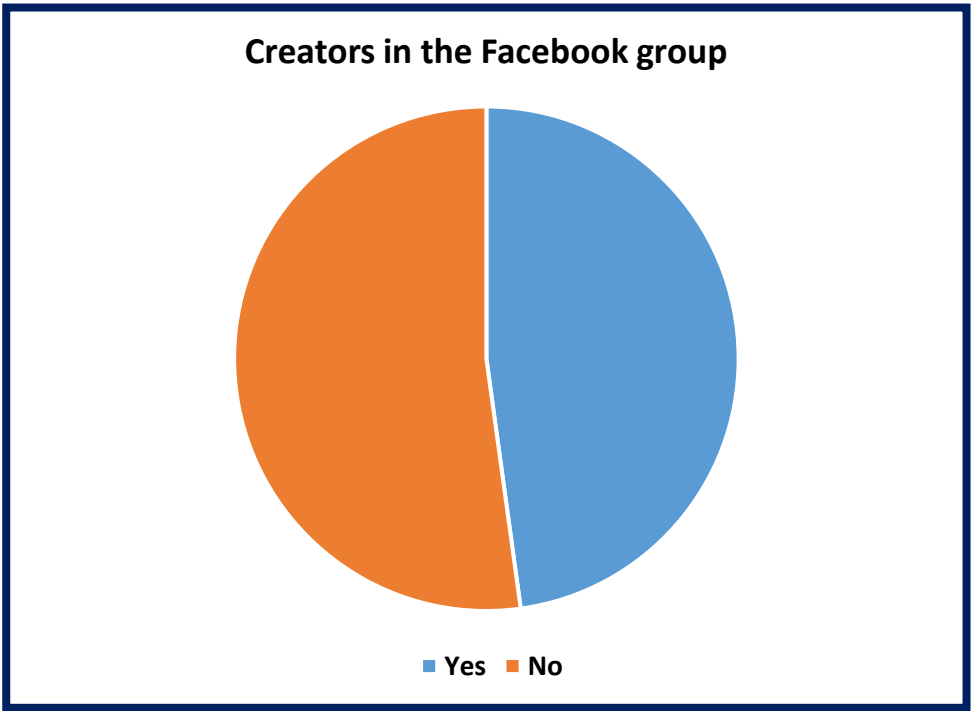


Figure 17 Proportion of creators who joined the *Exhibiting Pain* Facebook group

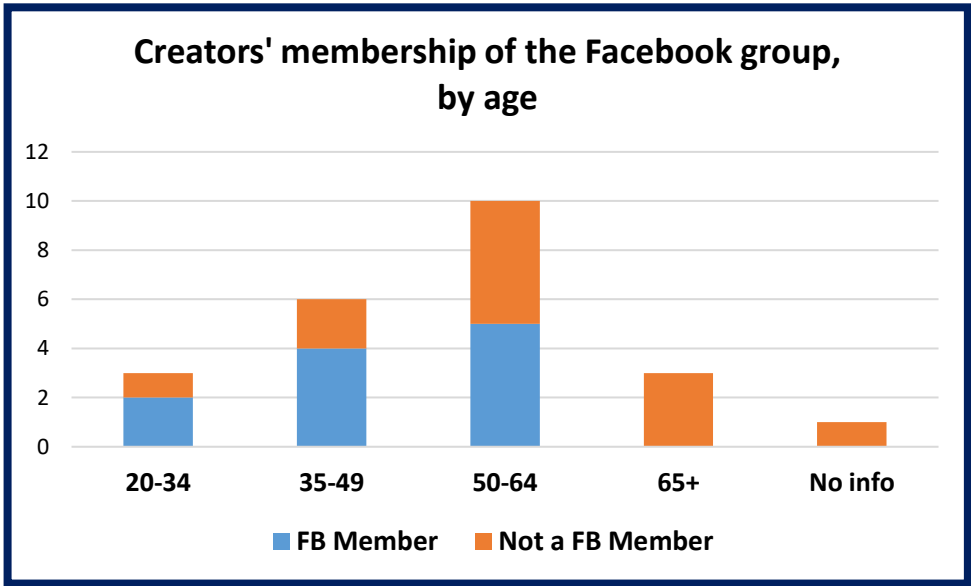


Figure 18 Creators' membership of the Facebook group, by age

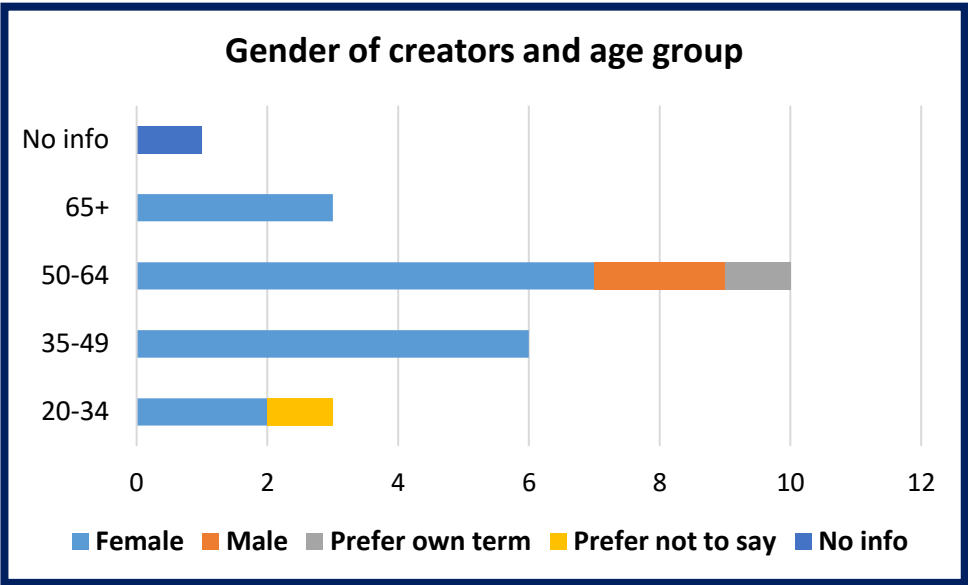


Figure 19 Age groups of creators by gender

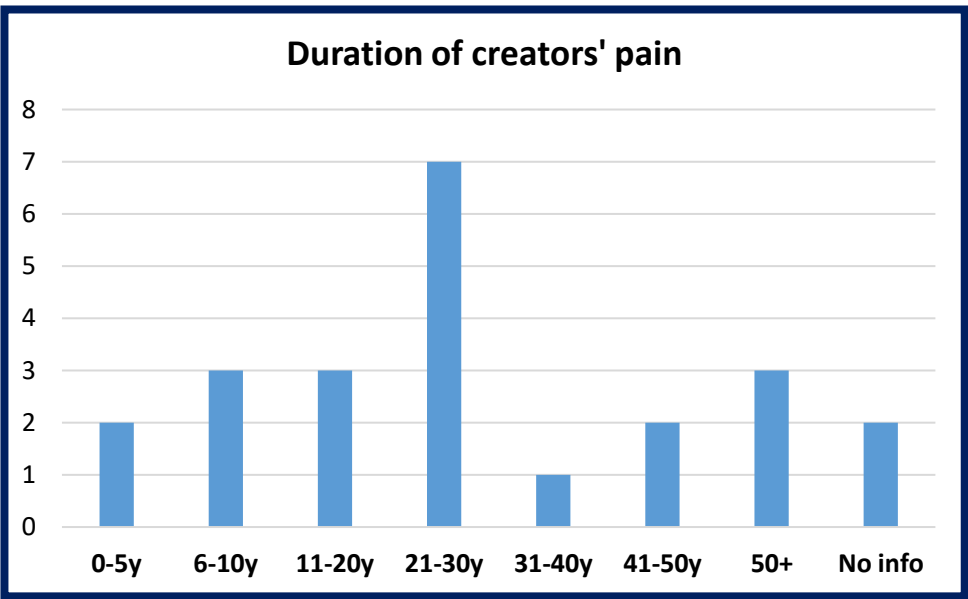


Figure 20 Duration of creators' pain

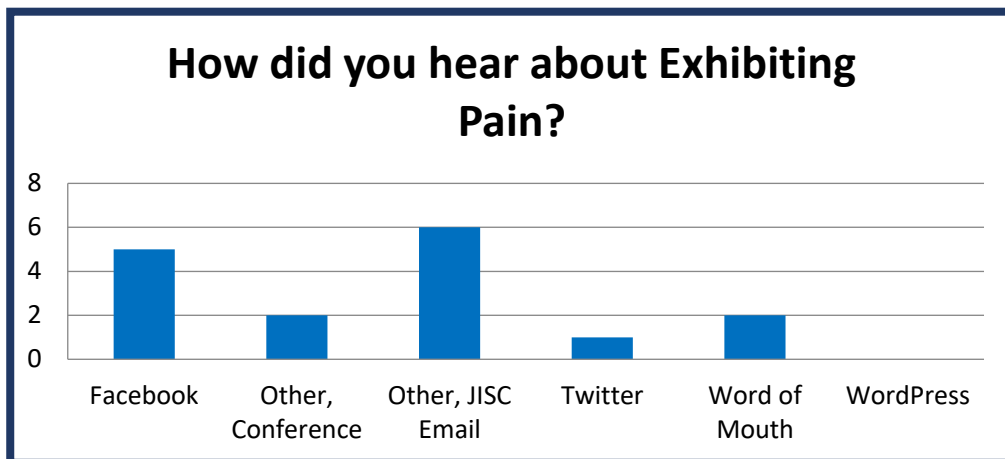


Figure 21 How audience members heard about *Exhibiting Pain*
(from Completed consent forms)

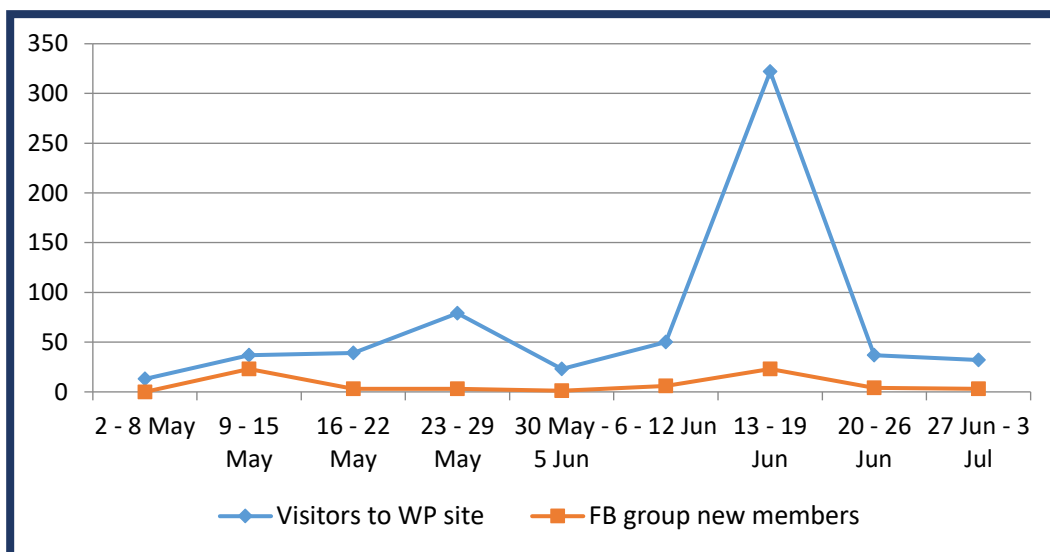


Figure 22 Levels of visitors to WordPress gallery and new Facebook members

Appendices

Pain status	VFF	Facebook
Has chronic pain (P)	6	25
Has chronic pain and a personal acquaintance of mine (P-PA)	2	5
No chronic pain (NP)	4	1
No chronic pain and a personal acquaintance of mine (NP-PA)	1	9
Pain status unknown (PU)	1	52
Pain status unknown and allied health or medical professional (PU-Pro)	2	-
Total	16 ³³	92

Table 2 - Pain status of audience members

³³ This figure excludes the VFF submitted which did not relate to the creative works but instead provided a detailed personal illness narrative

Appendix ii: Exhibits not featured in the text



Exhibit 22 *Eve and Mary Are Having Coffee*

[Untitled]
Marcela Zamborska

Here are some of my images from my art journal. This is the way I cope with my long term condition.



Exhibit 21 *[Untitled]*

Trigeminal Neuralgia Strikes

Carol Jay Levy

mixed media

7.25" (H) x 8.49" (W)

Trigeminal neuralgia comes out of the blue like a lightning bolt. It is also triggered for some by the slightest touch to the area of the face involved. It is a terrorist stalking and attacking, without warning or concern, leaving the sufferers in a constant state of fear: When will it hit me next?



Exhibit 23 *Trigeminal Neuralgia Strikes*

Appendix iii: Screenshots of the galleries



Figure 23 Screenshot of the WordPress gallery homepage



Figure 24 Screenshot of the Facebook gallery

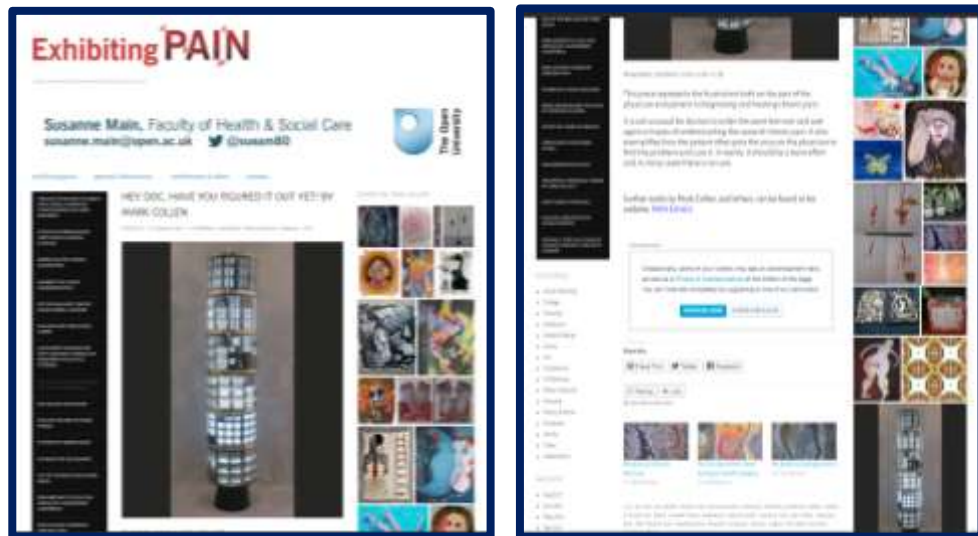



Figure 25 Screenshots of an exhibit on WordPress site



Figure 26 Screenshot of an exhibit on Facebook

Appendix iv: HREC approval



From Dr Louise Westmarland
Chair, The Open University Human Research Ethics Committee
Email louise.westmarland@open.ac.uk
Extension 01908 652462

To Susanne Main HSC

Project title
Exhibiting Pain: Interpretations of creative representations of persistent physical pain


HREC Ref HREC/2015/2166/Main
AMS ref
Submitted 19/11/15
Decision date 17/12/15

This memorandum is to confirm that the research protocol for the above-named research project, as submitted for ethics review, has been given a favourable opinion by the Open University Human Research Ethics Committee (HREC).

The Open University

Memorandum

Figure 27 HREC Approval



From Dr Louise Westmarland
Chair, The Open University Human Research Ethics Committee
Email louise.westmarland@open.ac.uk
Extension 01908 652462

To Susanne Main, HSC

Project title
Exhibiting Pain: Interpretations of creative representations of persistent physical pain (amendments)

HREC Ref HREC/2016/2166/Main
AMS ref
Submitted 02/06/16
Decision date 09/06/16

This memorandum is to confirm that the research protocol for the above-named research project, as submitted for ethics review, has been given a favourable opinion by the Chair's action on behalf of the Open University's Human Research Ethics Committee (HREC).

The Open University

Memorandum

Figure 27 HREC Approval for amendment to include Visitor Feedback Form

Appendix vi Participation and consent forms

Faculty of Health & Social Care

Consent form for persons participating in the research project

Exhibiting Pain

Please complete by typing text and return to: susanne.main@open.ac.uk

Name of participant:

Name of principal investigator(s): Susanne Main

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written statement, 'Exhibiting Pain Information sheet,' in plain language to keep.
2. I understand that my participation will involve posting comments online in a Facebook 'Closed' group and/or on a publicly visible WordPress blog page. This will be in response to an exhibition of art works, poetry, etc. about people's long-term physical pain. I may also share my thoughts to the researcher directly if I prefer, via email. I agree that the researcher may use the results as described in the plain language statement.
3. I acknowledge that:
 - (a) the possible effects of participating in this research have been explained to my satisfaction;
 - (b) I have been informed that I am free to withdraw from the project at any time prior to data analysis (as stated in the information sheets), without explanation or prejudice, thereby withdrawing consent from inclusion in any published research findings;
 - (c) the project is for the purpose of research;

(d) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements, and within the limits of what is possible with online data;

(e) I have been informed that with my consent the data generated will be stored securely electronically and will be destroyed after five years, unless archived;

(f) if necessary, any data from me will be referred to using a pseudonym in any publications arising from the research;

(g) I have been informed that a summary copy of the research findings will be forwarded to me, should I request this.

By signing this consent form, I am confirming that I am 16 years of age or older and that I will respect the creators' copyright of works exhibited.

I wish to receive a copy of the summary project report on research findings (please indicate): **Yes / No**

I may be reached by email at (optional):

Participant signature/name:

Date:

I would be grateful if you can also complete these questions about yourself. The information you provide will be stored securely on an encrypted electronic device.

1. Age

- ☐ 19 or under
☐ 20-34
☐ 35-49

☐ 50-64

☐ 65+

2. Gender

☐ Male

☐ Female

☐ Prefer not to say

☐ Prefer own term (please state):

3. What is your nationality?

4. In which country do you live?

5. What is your present occupation? (Please select no more than two)

Full-time student	<input type="checkbox"/>	Allied Health Profession	<input type="checkbox"/>
Research/Academia	<input type="checkbox"/>	Museum/Gallery	<input type="checkbox"/>
Medical Profession	<input type="checkbox"/>	Arts profession (e.g. artist, writer)	<input type="checkbox"/>
Not presently in paid work (e.g. retired, unemployed, unable to work, full-time parent)	<input type="checkbox"/>	Other profession (Please state, e.g. ICT, retail, banking):	<input type="checkbox"/>

6. Do you personally experience long-term physical pain?

If yes, you can enter information about it here, if you wish to.

7. Do you have any other connection to long-term physical pain? For example, working in a related field, or have a friend or family member with long-term pain.

8. Do you take part in any creative activities? For example, knitting, sewing, painting, creative writing, musical instrument.

Yes/No (Delete as applicable)

9. Have you visited a museum or exhibition in the last year?

Yes/No (Delete as applicable)

10. How did you hear about *Exhibiting Pain*?

Twitter	<input type="checkbox"/>	Facebook	<input type="checkbox"/>
Word Press	<input type="checkbox"/>	Word-of-mouth	<input type="checkbox"/>
Other (Please state): 			

Faculty of Health & Social Care

Consent form for creators* participating in the research project

Exhibiting Pain

Please complete by typing text and return to: susanne.main@open.ac.uk

Name of participant/creator:

Name of principal investigator(s): Susanne Main

1. I consent to participate in this project, the details of which have been explained to me. I have been provided with written statements, 'Exhibiting Pain Information sheet' and the 'Creator's information sheet', in plain language, to keep.
2. I understand that my participation will involve the sharing of my creative work (art piece, poem, music, etc.) in online exhibitions about people's long-term physical pain. I agree that the researcher may use the findings, as described in the plain language summary, but that copyright of the creative piece remains mine.
3. I understand that I may also participate in the online discussions about the creative pieces, if I choose to. I agree that the researcher may use the findings, as described in the plain language statement.
4. I acknowledge that:
 - (a) the possible effects of participating in this research have been explained to my satisfaction;
 - (b) I have been informed that I am free to withdraw from the project at any time, without explanation or prejudice, and to withdraw consent from my contributions being quoted in research reports;

(c) I have been informed of my right to withdraw my creative piece from the exhibitions/research at any time, without explanation or prejudice, and that all comments and responses to my creative work will be destroyed;

(d) the project is for the purpose of research;

(e) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements, and within the limits of what is possible with online data;

(f) I have been informed that, with my consent, the data generated will be stored securely electronically and will be destroyed after five years, unless archived;

(g) if necessary, any data from me will be referred to using a pseudonym, in any publications arising from the research;

(h) I understand that my creative work and any accompanying label or description will need to be vetted by the researcher, to ensure it is appropriate to be included in the exhibitions;

(i) I have been informed that a summary copy of the research findings will be forwarded to me, should I request this.

Please select from the following options on where and how you would like your work to be featured in *Exhibiting Pain*:

I wish for my creative work to be included in (please indicate as appropriate. Either one or both are possible):

☐ Facebook 'Closed' *Exhibiting Pain* group (permission to join must be granted before content can be viewed)

AND/OR

☐ WordPress *Exhibiting Pain* blog site (publicly visible)

Would you like a faint 'Watermark' placed across the image of your work?

Yes / No

If you would like to provide a title and text to accompany your work, please attach as a separate document, insert here or at end of document.

Please state how you would like your name (or pseudonym) included in the exhibition(s):

I wish to receive a copy of the summary project report on research findings (please indicate): **Yes / No**

I may be reached by email and/or phone at:

By signing this consent form, I am confirming that I am 16 years of age or older and that I will respect the creators' copyright of works exhibited.

Participant signature/name:

Date:

I would be grateful if you can also complete the following questions about yourself. The information you provide will be stored securely on an encrypted electronic device.

- 11. Age**
- ☐ 19 or under
- ☐ 20-34
- ☐ 35-49
- ☐ 50-64
- ☐ 65+

- 12. Gender**
- ☐ Male
- ☐ Female
- ☐ Prefer not to say
- ☐ Prefer own term (please state):

13. What is your nationality?

14. In which country do you live?

15. What is your present occupation? (Please select no more than two)

Full-time student	<input type="checkbox"/>	Allied Health Profession	<input type="checkbox"/>
Research/Academia	<input type="checkbox"/>	Museum/Gallery	<input type="checkbox"/>
Medical Profession	<input type="checkbox"/>	Arts profession (e.g. artist, writer)	<input type="checkbox"/>
Not presently in paid work (e.g. retired, unemployed, unable to work, full-time parent)	<input type="checkbox"/>	Other profession (Please state, e.g. ICT, retail, banking):	<input type="checkbox"/>

16. If you would like to provide any information about your persistent physical pain, that you consider relevant to this study, you are welcome to do so here.

17. How long have you experienced long-term physical pain?

- 18. Do you have any additional connection to long-term physical pain?
For example, working in a related field or through a friend or family member.**
- 19. Prior to developing long-term pain, did you have an interest in the arts or creative activities?**
- 20. Why did you begin to represent your experiences with pain creatively?**
- 21. Did you have a particular audience in mind when creating the piece(s)?**
- 22. Do you have any further thoughts or comments you'd like to make relating to this research or your experience using creativity in relation to your long-term pain?**

Appendix vii: Visitor Feedback Form

Exhibiting PAIN

Your consent is assumed by your completion of this questionnaire but it is helpful to me to receive the completed consent form also. Please email me your completed form: susanne.main@open.ac.uk

Please don't feel that you need to answer all of these questions but any details you provide will be invaluable to my research, thank you.

- 1. Did any particular works stand out and why?**
- 2. Were there any you moved past quickly?**
- 3. Does the exhibition make you think differently about the experience of living with persistent pain?**
- 4. How do the colours used, or imagery, affect your view of persistent pain?**
- 5. Is there anything you would like to say to a creator, if you could?**
- 6. Did you read the accompanying text, was it helpful?**
- 7. Do you have any further thoughts about viewing this exhibition and the potential for such projects?**

